

# **Child and parental perspectives on communication and decision-making in pediatric chronic kidney disease: a focus group study**

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## **Abstract**

**Background and Objectives:** Effective communication and shared decision-making improves quality of care and patient outcomes, but can be particularly challenging in pediatric chronic disease as children depend on their parents and clinicians to manage complex healthcare and developmental needs. We aimed to describe the perspectives of children with chronic kidney disease (CKD) and their parents with regard to communication and decision-making.

**Study design:** Qualitative study

**Setting and Participants:** Children with CKD (n=34) and parents (n=62) from six centers across six cities in Australia, Canada and the United States participated in 16 focus groups.

**Analytical Approach:** Transcripts were analyzed thematically.

**Results:** We identified four themes: (1) disempowered by knowledge imbalance (unprepared and ill-informed, suspicion of censorship, inadequacy as technicians); (2) recognizing own expertise (intuition and instinct unique to parental bond, emerging wisdom and confidence, identifying opportunities for control and inclusion, empowering participation in children); (3) striving to assert own priorities (negotiating broader life impacts, choosing to defer decisional burden, overprotected and overruled, struggling to voice own preferences); and (4) managing child's involvement (respecting child's expertise, attributing 'risky' behaviors to rebellion, protecting children from illness burden).

**Limitations:** Only English-speaking participants were recruited, which may limit the transferability of the findings. We collected data from child and parent perspectives, however clinician perspectives may provide further understanding of the difficulties of communication and decision-making in pediatrics.

**Conclusions:** Parents value partnership with clinicians and consider long-term and quality of life implications of their child's illness. Children with CKD want more involvement in treatment decision-making but are limited by vulnerability, fear, and uncertainty. There is a need to support the child to better enable them to become partners in decision-making and prepare them for adulthood.

Collaborative and informed decision-making that addresses the priorities and concerns of both children and parents is needed.

**Index words:** shared decision-making, patient-centred care, pediatrics, chronic kidney disease, chronic disease, qualitative research, communication, participation, involvement, treatment decision-making, mismatched priorities

**Non-technical summary:** We conducted a multi-national focus group study to explore child and parent perspectives and preferences about communication and decision-making. Our data revealed children with CKD and their parents perceived a knowledge asymmetry, which for some limited their capacity and confidence to contribute to decisions and communicate their concerns and goals. Experiential learning and gaining familiarity with the clinical setting enabled some parents to trust their ‘gut’ instincts, empowering them to communicate concerns, however some children felt that their preferences were sometimes ignored or dismissed by their parents and clinicians. Parents were challenged with the tension between allowing their child decisional autonomy and taking responsibility to protect their child from the illness burden. Our study highlights the potential for miscommunication and differing priorities between parents and children and provides opportunities for clinicians to improve communication, partner with patients to empower them to become active decision-makers, and recognize parent and child expertise.

## **Introduction**

Shared decision-making is a cornerstone of patient-centered care and improves patient knowledge, satisfaction, adherence, and outcomes(1-5). However, this process is particularly challenging in pediatrics because of the dynamic and complex relationship triad that encompasses the autonomy of the patient, legal authority of the parent, and the beneficence and clinical acumen of the physician(1, 2, 6-9). This complexity is compounded by the constantly changing nature of these relationships as the child matures.

Shared decision-making is “an interactive process in which patients (including families) and physicians simultaneously participate in all phases of the decision-making process and together arrive at a treatment plan to be implemented”(2). However, integrating the often conflicting priorities of the child, parent, and clinician for competing treatment options is not straightforward(2). Failure to involve patients and families in decision-making can exacerbate disempowerment, fear, decisional conflict, and disengagement from healthcare, which can jeopardize safety, quality of care and outcomes for children(2-5, 10-13). Despite this, evidence on child and parental perspectives on communication and decision-making in pediatrics is sparse(2, 14-16).

The challenges in communication and shared decision-making are highly relevant in childhood chronic kidney disease (CKD). Children with CKD have a 30-fold increased risk of mortality compared with the age-matched population, and are at risk of serious comorbidities and impaired quality of life, which can limit their perceived capacity to participate in shared decision-making(3, 17). Limited evidence exists on communicating and shared decision-making with children and families dealing with chronic and complex disorders(15, 16, 18). This study aimed to describe the child and parental perspectives on communication and decision-making in CKD to identify

opportunities to improve shared decision-making, with an ultimate goal of improved care and better outcomes for children with CKD and their families.

## **Methods**

This focus group study was conducted as part of the Standardized Outcomes in Nephrology – Children and Adolescents (SONG-Kids) Initiative(19). We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) to report this study(20).

### *Participant selection*

Parents of children aged 0-21 years and children aged 8-21 years with stage 1-5 CKD, receiving dialysis, or who had received a kidney transplant were eligible to participate. All participants were English-speaking to minimize disruptions to the dynamic of the focus group discussions and due to the lack of resources for multilingual trained facilitators.

Participants were recruited from three centers in Australia (n=44), two centers in Canada (n=16), and one center in the United States (n=36). The site investigators were asked to apply a purposive sampling strategy when selecting patients and their families from their database to ensure a broad range of demographic (age, gender, socioeconomic status) and clinical (CKD stage, diagnosis) characteristics. The researchers approached participants who gave permission to be contacted to provide the time and venue details to participate in the focus group. Informed consent was obtained from participants aged over 18 years. Parental consent and written assent was obtained for those aged under 18 years. Participants received \$50 reimbursement (in their local currency) to cover travel costs. Ethics approval was provided by the Institutional Review Board of all participating centers (Item S1).

### *Data Collection*

Two-hour focus group discussions were conducted separately for parents and children, externally to their treating hospitals, from June 2016 to August 2017, until data saturation. All groups were audio-recorded and transcribed verbatim. Question guides were developed from the literature and discussion with the investigators (Items S2 and S3). One investigator (CSH, AT, TG) facilitated the group while a second investigator (AJ, LJ, AT, TG, AR) took field notes.

### *Analysis*

The transcripts were entered into HyperRESEARCH software to facilitate qualitative data analysis. TG inductively coded the transcripts line-by-line using thematic analysis and principles from grounded theory to identify concepts related to participants' perspectives on communication and decision-making(21). Preliminary themes were discussed and revised with AT, CH and SB who had independently read the transcripts. Investigator triangulation ensured that the analysis captured the full range and breadth of the data. A thematic schema was developed to show the relationships among themes (Figure 1).

### **Results**

In total, 62 parents and 34 children participated in 16 focus groups. Participant characteristics are shown in Tables 1 and 2. Parents were aged from 24 to 58 years and most were mothers (47, 76%). Twenty-five (40%) parents had children who had CKD stage 1-5, 14 (23%) had children on dialysis, 22 (35%) had children with a kidney transplant and one parent did not report CKD stage of their child. Seven (11%) parents had a child with CKD aged younger than 8 years. Children ranged from 8

to 21 years (including younger children aged 8-12 years, adolescents aged 13-17 years and young adults aged 18- 21 years), 19 (56%) were male, 17 (50%) had CKD stage 1-5, 5 (15%) were on dialysis, and 12 (35%) had received a kidney transplant. Twenty-nine children had at least one parent who also participated in the study.

We identified four themes: disempowered by knowledge imbalance; recognizing own expertise; striving to assert own priorities; and managing child's involvement. The respective subthemes are described in the following section with reference to the relevant participant group (parent, child) and relationship context (within the triad). Selected quotations to support each theme are available in Table 3. Figure 1 shows the relationships among themes and subthemes.

### **Disempowered by knowledge imbalance**

*Unprepared and ill-informed:* Uncertainty surrounding their child's prognosis meant some parents felt inadequately warned about their child's need for treatment (e.g. transplant). Some believed they were given "false hope" and "unrealistic" expectations regarding medication side-effects and surgery recovery, while others felt they were "getting railroaded into things" (e.g. biopsies) by clinicians. Parents wanted "more education" and fewer "medical terms" to inform decision-making. Younger children struggled to comprehend information from parents and clinicians (e.g. blood results) and wanted more information "in words that [they] could understand". Some adolescents had unanswered questions about their future, such as how potential treatments may impact fertility and "what happens after" graft failure.

*Suspicion of censorship:* Some parents speculated that clinicians withheld certain information (e.g. graft rejection) or would not discuss new treatments, such as stem cell therapy or new trials, when they asked about them. Some younger children and adolescents suspected they "didn't get told

everything” about their CKD and some thought their parents did not want to disclose the severity of their illness.

*Inadequacy as technicians:* The perceived knowledge imbalance between clinicians and parents further served to disempower parents as they felt forced to relinquish their caregiver role to clinicians and accept treatments that they did not necessarily prefer. For example, some parents believed they did not have the technical expertise required to choose less disruptive and invasive treatments such as home peritoneal dialysis and were therefore forced to accept in-center hemodialysis. This resulted in feelings of guilt and helplessness in not being able to contribute to their child’s care.

### **Recognizing own expertise**

*Intuition and instinct unique to parental bond:* While clinicians were acknowledged as “the expert”, parents learnt to regard their own instinct, a “mum gut”, as equally important. Parents could detect signals in their child, for example “dry lips”, “heavy breathing”, or “not growing”, that were ultimately determined to be clinically important. At times, parents believed they had to “convince” or “pressure the doctors” to investigate their child’s symptoms and were distressed and frustrated when they felt ignored.

*Emerging wisdom and confidence:* As they became more familiar with CKD and the clinical setting some parents developed knowledge and skills that enabled them to better manage their child’s care and were thus able to opt for preferred treatments options, such as home dialysis. A few became increasingly sceptical about treatment decisions made by clinicians, particularly if they resulted in detrimental outcomes or were perceived as unnecessary.

*Identifying opportunities for control and inclusion:* As parents developed confidence in their own expertise they pursued opportunities for involvement and control. Some challenged the need for

repeating invasive procedures such as biopsies, or argued to change their child's immunosuppression dose after "seeing the side effects." Having to face uncertainty and burden of treatment, some adolescents and young adults sought autonomy in making decisions and managing their health and treatment where possible. They wanted to contribute to decisions about medications, diet, and invasive interventions such as dialysis or surgery. Some younger children felt their parents dominated interactions with clinicians which hindered their ability to communicate with clinicians directly.

*Empowering participation in children:* Parents appreciated when clinicians encouraged independence and responsibility in their child for self-management. While some children were satisfied with how their clinicians incorporated their preferences in their treatment, some adolescents were "worried" about their lack of involvement and how they would cope with the role of primary decision-maker as an adult – "at the moment it's in your mum and dad's hands, when you get older you've got to take it into your own hands."

### **Striving to assert own priorities**

*Negotiating broader life impacts:* Parents considered the impact of treatment decisions on their child more "broadly" in terms of the long-term risks and felt clinicians tended to focus on immediate clinical outcomes. They questioned "textbook" decisions that often focused on survival, and instead wanted to draw attention to impact on "quality of life". For example, one mother refused bladder augmentation to avoid her child having to be "catheterized for life." Children wanted to "hang out with friends, go out, have fun, be normal kids," but felt restrictions imposed by their parents and clinicians (e.g. diet and physical activity) and the treatment and symptom burden of CKD limited their freedom of choice.

*Choosing to defer decisional burden:* While parents valued being involved in decision-making in many instances, they were sometimes grateful for the option to ease their own decisional burden by deferring to physicians who were trusted to “know what they were doing.” As CKD was “scary” and involved complex treatment decisions in sometimes life-threatening situations, younger children often felt they lacked sufficient knowledge to determine the best course of action, and children of all ages looked to clinicians and parents for support and “reassurance”.

*Overprotected and overruled:* Adolescents and young adults were frustrated when their parents were “super protective” and did not trust them to make the right choice as this limited their involvement in decisions that impacted their lifestyle. Children believed they often had no choice regarding treatments and accepted they “have to” “get needles”, “growth hormones”, “go on dialysis” or “have surgery.” However, they were upset and sometimes objected when told by parents not to “play contact sports,” “eat certain foods,” or “do active things” with their friends, particularly when they believed these did not pose any additional risk.

*Struggling to voice preferences:* Some children had trouble voicing their preferences because they believed they were viewed as unimportant, particularly when they conflicted with priorities of parents and clinicians. Some refrained from asking questions to avoid appearing “stupid” or because they felt “too shy” to ask. Some children felt unfairly judged or accused by parents and clinicians, for example one adolescent explained that they could not take medications because it made them “sick”, but were made by their parents and physician to see a psychologist for non-adherence.

### **Managing child’s involvement**

*Respecting child’s expertise:* Some parents valued their child’s experience as the patient (e.g. recognizing symptoms) and said that their child “makes the decision, because it’s [their] body,”

however, they sometimes felt the need to intervene if they perceived their child's preference had unacceptable risks or consequences. One mother overruled her adolescent's preference for an open nephrectomy, and instead elected to have laparoscopic surgery to minimize risk and recovery time.

*Attributing 'risky' behaviors to rebellion:* Decisions including refusing to take medication or attend appointments were blamed on "teenage rebellion" by some parents. Some were concerned they couldn't "make [their child] understand" that having CKD meant their choices had more severe consequences than their well peers'. Some parents "struggled" with their child's non-adherence, and attributed this behavior to adolescent risk-taking and defiance.

*Protecting children from illness burden:* As CKD is a lifelong condition that requires invasive interventions, and is associated with serious co-morbidities, parents wanted to carry the emotional burden of the disease. They debated keeping their child "in the dark" about their prognosis and potential treatments. Some struggled to find a balance between over-protecting their child and giving them the freedom "to be a kid" and participate in 'normal' activities.

## **Discussion**

Children with CKD and their parents perceived a knowledge asymmetry, which for some limited their capacity and confidence to contribute to decisions, manage treatment, prepare for potential complications, and communicate their concerns and goals. Some parents believed that clinicians did not communicate comprehensive information about their child's disease, which meant they were unprepared to manage comorbidities and unable to choose treatment options to minimize the risk of complications and side effects. Some suspected clinicians avoided discussion on specific topics particularly in relation to transplant outcomes such as rejection. As children matured, they wanted more information about their disease communicated in ways they could understand. While some adolescents and young adults had a better clinical understanding and could take on more

responsibilities (e.g. managing medications), some younger children also wanted to be involved in their care and decisions, especially when it constrained their social freedoms. Children sensed that their parents did not want to talk to them about the severity of their disease and prognosis.

Experiential learning and gaining familiarity with the clinical setting enabled some parents to trust their 'gut' instincts, empowering them to communicate concerns about the broader impact of treatments on their child's life, even if it conflicted with the clinician's recommendations. Other parents elected to defer decision-making to their trusted clinician to avoid the pressure of having to make difficult decisions, and were grateful for the comfort and reassurance they provided. The desire for inclusion and control among children with CKD was apparent for decisions that impacted their ability to be "normal kids". They wanted to know about outcomes beyond childhood, including their ability to start a family. Some children sought to regain control through self-management, but felt that their preferences were sometimes ignored or dismissed by their parents and clinicians. This is highlighted by the absence of data from the child perspective recognizing their inherent expertise as the patient.

Parents were challenged with the tension between allowing their child decisional autonomy, and taking responsibility to protect their child from the burden of illness and consequences of high-risk choices and behavior. While some parents claimed they allowed their child to make the decisions, they also believed they should filter communication between the clinician and child, and make the final decision if they disagreed with their child's preferences. Our study also revealed potential miscommunication and differing interpretations between parents and children. For example, one mother attributed her child's non-adherence to "teenage rebellion", whereas the adolescent explained their refusal to take medications was because it made them feel ill. One father explained that his child "doesn't bother [being involved in treatment decisions]" because "she doesn't really have that

understanding”, while the younger child explained she “wanted to know more...so [she knows] what is happening in [her] body” but felt “too shy to ask.”

As found in previous studies across other childhood chronic conditions, parents may strive to protect their children from the burden of ‘knowing’ by managing communication about their disease and treatment, however this can mean that children are inadvertently denied opportunities for involvement in their care(7, 14, 22-26). Children want to be aware of what is happening in their own bodies, involved in their own care, and empowered to address concerns and goals that are important to them, particularly as they grow up(6, 12, 15, 24, 27-30). They also desire experience in decision-making through incremental involvement to be better prepared for transition into adulthood when they will no longer rely on their parents as proxies for their health care decisions and responsibilities(7, 18, 23, 30, 31).

Mismatches between patient and clinician priorities have been recognized since the early 1960s, resulting in the paradigm shift in the approach to healthcare – from paternalism to partnership(15, 32-36). In pediatrics, differences between parent and clinician priorities have been well established(2, 15, 28, 37). Shared decision-making models have been developed to manage this discordance and while some aspects (e.g. multi-directional information exchange, presenting all options clearly, determining preferences for involvement(10, 32-35, 38-40)) may be applicable to the pediatric setting, they do not specifically address the power imbalance the child faces in the triad(14, 15, 32, 33, 35). The Typology of Youth Participation and Empowerment (TYPE) Pyramid developed for youth empowerment in health promotion suggests a pluralistic approach to youth participation when adults and youth transactionally share control, allowing young people to leverage “social capital” and experience from adults, while still allowing them to defer to adults if desired(41). Aspects of this framework may be useful for researchers and clinicians working in pediatric CKD, however it may not adequately account for the uncertain trajectory of CKD and may not address the

changing needs of a developing child. There remains a need to bridge the gap from the parent/clinician to the child, to consider the child's preferences separately from their parents' and to identify effective strategies or frameworks to elicit and integrate the child's perspective in decision-making(9, 13, 18, 36, 42, 43).

This study was multinational and offers in-depth insights gained from perspectives of a diverse group of children with CKD and parental caregivers. We achieved data saturation, and used investigator triangulation in the analysis to ensure the themes reflected the breadth and depth of the data. However, there are some potential limitations. All participants were English-speaking and from high income countries, therefore transferability of the findings to other populations and settings is uncertain, but we note that participants were diverse in terms of country of birth and socioeconomic status. Moreover, communication issues experienced are likely to be exacerbated in contexts where all parties in the triad do not speak the same language. While participants likely experienced different types of care and education across different centers, our findings show themes were consistent and relevant across all centers. We acknowledge that we included only one patient on hemodialysis at the time of the study so the views of prevalent patients on hemodialysis may not have been captured extensively. However, children and parents of children previously on hemodialysis discussed their past experiences with hemodialysis and five parents who participated had a child receiving hemodialysis. Our data reflect the views of only two out of the three people in the decisional triad. Clinician perspectives may help to better understand where and why breakdowns in communication occur.

Our findings reveal opportunities for communication training for clinicians to 1) improve transparency in communication, 2) promote partnership with their pediatric patients, and 3) recognize patient and parental expertise. Ensuring parents and children understand all the treatment options (including potential need for treatment), and how they might impact medical, social

participation, and longer-term quality of life outcomes may help to alleviate anxiety over uncertainties and suspicion of censorship, and enable them to prepare for the challenges of living with a chronic disease(2, 8, 23, 28). Partnering with parents to engage children in their own care would involve providing them with appropriate resources and education, creating opportunities for them to be heard, and advocating for their preferences(2, 44). There is also a need to explicitly acknowledge the expertise that parents and children can bring to the decision-making process and to consider these in relation to their preferences when making decisions(14, 15, 32, 38, 44).

The American Academy of Pediatrics and the United Nations advocate to involve children in decisions about their health and treatment(2, 7, 8, 16). However, the lack of child-centred interventions for decision-making denies children a voice in their own care(16). Evidence from the adult population suggests decision coaching in conjunction with decision aids may be effective in increasing participation in decision-making, increasing knowledge, improving alignment of decisions with patient values, and decreasing decisional conflict(12, 45). A systematic review of interventions to support decision-making in pediatrics found that decision-coaching (i.e. individualized, facilitated discussion to prepare the patient for upcoming decision-making(12, 45)) had modest effects in improving the decision-making process, decision alignment between parents and children and satisfaction regarding being informed about options(12). Visual aids, rephrasing, turn-taking, and role-playing, may also be effective for improving communication in children with CKD(13, 22, 46). Journaling can be an effective method to engage children and enables them to express their private experiences and emotions safely(47, 48). Further research is needed to assess the effectiveness of different strategies and interventions for communication and decision-making in the pediatric CKD population, and across disease stages. We suggest the need for more studies to improve communication and shared decision-making that target all three members of the decisional triad(12, 18). An online portal or mobile phone application journaling tool where children can express their preferences, report their symptoms, access decision supports and describe their feelings may

empower children to become more active in their health. Children could determine what information they want to share with their parents and health care professionals through a messaging or permission system that could give parents and clinicians access to selected content. We suggest involving children and parents in the development, implementation and evaluation of future interventions to support communication and decision-making in this context, and that future research include a specific focus on their perspectives on decision-making and relationship with multidisciplinary team members including psychologists, social workers, youth workers, and play therapists(18, 30).

A perceived lack of knowledge and poor communication disempowers children and parents from becoming active participants in their care. Parents want comprehensive information in plain language and recognition of their expertise, and are motivated by a strong desire to protect their child. Children want “reassurance” and to understand the long-term implications of their disease and treatment, and involvement in decisions that impact their ability to live a “normal” life, however they struggle to voice their preferences. An absence of data on the child’s expertise as the patient highlights the need to invest in building this expertise incrementally and in line with their development to better equip them to become partners in decision-making and prepare them for adulthood. Effective interventions to support communication and shared decision-making are needed. These can lead to better knowledge and understanding of the condition(15, 16, 18, 49) as well as improved health outcomes(5, 8, 22, 39, 50), improved decisional quality(2, 15, 16, 28) and improved patient satisfaction(5, 14, 16, 51).

**Supplementary Material:**

Item 1: Participating Sites and Institutional Review Boards

Item 2: Child question guide

Item 3: Parent question guide

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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 (young children)	10 (29)
13-17 (adolescents)	20 (59)
18-21 (young adults)	4 (12)
Current CKD** treatment stage	
CKD 1-5	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)

\*Other includes: Mexico, New Zealand; \*\*CKD: chronic kidney disease

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

Characteristics	n (%)			
Gender				
Male	13 (21)			
Female	49 (79)			
Carer 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)				
	US	CAD	AUD	Total
\$0-39,000	5	1	2	8 (13)
\$40,000 - \$59,999	2	1	7	10 (16)
\$60,000 - \$84,999	0	6	6	12 (19)
\$85,000-\$124,999	7	2	3	12 (19)
>\$125,000	2	1	5	8 (13)
Not reported	5	0	7	12 (19)
Child's age (years)				
0-7	7 (11)			
8-12	18 (29)			
13-17	32 (52)			
18-21	3 (5)			
Not reported	2 (3)			
Child's CKD** treatment stage				
1-5	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 <sup>^</sup>	9 (15)
No reported or not known	17 (28)

† Twenty (32%) parents 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; <sup>^</sup>Other includes: Cystinosis, Eagle Barret Syndrome, IGA Nephropathy, Scleroderma, Neurogenic bladder, bladder obstruction, reflux

**Table 3: Selected illustrative quotations**

Theme	Illustrative Quotations ( <i>participant, child's age, CKD stage, country</i> )
<b>Disempowered by knowledge imbalance</b>	
Unprepared and ill-informed	<p>They got us bits and pieces of information. It was more medical. Some of it was hard for us to understand. <i>(Father, 8-10y, transplant, Australia)</i></p> <p>I never felt like I had enough information about the procedures. Sometimes I just feel like I'm getting railroaded into things. <i>(Mother, 13-17y, transplant, Australia)</i></p> <p>I think parents should be given more education, so that we know what's going on, and we know more about the disease. We lack a lot of outcomes of the studies you do, we should be informed about that. <i>(Father, 8-10y, CKD, Australia)</i></p> <p>It's also a Catch-22 because we want to keep his kidneys as long as we can, keep it healthy for as long as we can. But at the same time, once he reaches 18, he's no longer a child, so finding a kidney is going to be harder. <i>(Mother, 13-17y, CKD, US)</i></p> <p>If you had just told me that was a side effect I'd be prepared. <i>(Grandmother, 13-17, CKD, Australia)</i></p> <p>They were saying things like, oh you won't know yourself, it'll be a magical experience, you'll get to do all these things you've never done, it's going to be wonderful to have this life you've never had, and then it hasn't been. <i>(Mother, 13-17, transplant, Australia)</i></p> <p>So giving false hope, really...instead of a more realistic, instead of painting a fantasy that everything's going to be better. <i>(Mother, 13-17y, CKD, Australia)</i></p> <p>For a few years I thought he only had one kidney and that was it. And then, at one appointment, she just said, "Oh, well when he has his transplant", and I was like, "What are you talking about?" That was kind of when I found out. <i>(Mother, 13-17y, CKD, US)</i></p> <p>I wanted to know if I would get better, but the answer she said didn't actually make any sense. Something printed out in words that I could understand [would be useful]. <i>(Girl, 8-12y, CKD, Australia)</i></p> <p>When you have a kidney transplant they say it can last up to 15 years. But I don't know what happens after that. <i>(Girl, 13-17y, transplant, US)</i></p>
Suspicion of censorship	<p>They say you get kidney rejection episodes which can scar the kidney. I think we've had one, but they haven't told us. <i>(Mother, 8-12y, transplant, Australia)</i></p> <p>[For] his disease [they] are doing cure trials in America starting from this year, but the doctors won't acknowledge it when I bring it up. <i>(Mother, 13-17y, dialysis, Australia)</i></p> <p>They didn't say anything, they just said, "His blood pressure is too high, and you need to go to the Emergency Room." <i>(Mother, 18-21y, transplant, US)</i></p> <p>The biggest challenge that I see- and the biggest impact to [her daughter's] life- is her delayed development and her learning disabilities, things that I'm now told go hand-in-hand with transplantation and kidney failure. <i>(Mother, 13-17y, transplant, Canada)</i></p> <p>My mom was crying about it, and I was like, "Why are you crying, what's going on?" And she was like, "You might have a transplant". And I was like, "What's that?" And she wouldn't tell me because I was young. <i>(Girl, 13-17y, transplant, US)</i></p> <p>I feel like sometimes like I don't get told everything. But I don't know if I am or not. <i>(Girl, 13-17y, CKD, Australia)</i></p>
Inadequacy as technicians	<p>They gave me two options, whether you want to do peritoneal dialysis or haemodialysis, but I chose haemodialysis because I wasn't confident that I could do the dialysis at home. <i>(Mother, 13-17y, transplant, Australia)</i></p> <p>It is the most helpless feeling. You can't do nothing. <i>(Father, 13-17y, transplant, Australia)</i></p> <p>They're like, "and you're going to have to monitor her blood pressure but don't worry, we're going to get you a cuff". Within a week we were going by ambulance back to the hospital because no one told me how to work the blood pressure cuff. <i>(Mother, 13-17y, CKD, US)</i></p>
<b>Recognizing own expertise</b>	
Intuition and instinct unique to parental bond	<p>I'm following my 'mum gut' and I think they respect that. <i>(Mother, 8-12y, CKD, Australia)</i></p> <p>The only reason I brought him into the hospital that day was because he was breathing more heavily than usual. <i>(Mother, 0-7y, dialysis, Canada)</i></p> <p>He had dry lips, and I thought 'hang on, you drink so much, why are your lips always cracked?' So I took him to my local GP. Luckily he listened to me. He was down to 29 per cent function, that's how we found out. The pediatrician said if I'd asked her it would've been a straight out no, but I taught her a lesson now that any mum that's got any queries, that she will listen to. <i>(Mother, 8-12y, CKD, Australia)</i></p> <p>So the struggle with our local MDs, to get us here. She had shown all these signs and symptoms. I went to see pediatricians, I went to see doctors but nothing, they kept saying, "Oh, she's going to grow, she's this, she's that, blah, blah". <i>(Mother, 8-12y CKD, Canada)</i></p> <p>It took me pressuring the doctors, and pressuring the doctors, to figure out what was going on with her. <i>(Mother, 13-17y, dialysis, US)</i></p>

Emerging wisdom and confidence	<p>I think you sometimes have to put your views [forward]. He [doctor] is the expert. [However] when you are at home you know what is going on. <i>(Mother, 8-12y, transplant, Australia)</i></p> <p>You know your child. <i>(Mother, 13-17y, transplant, Australia)</i></p> <p>Initially whatever they would say, we would say okay, but now we question everything Why? What is that going to tell us? Why are you doing that? Is there any risk? Why do you think he needs it? I always ask. <i>(Mother, 8-12y, transplant, Australia)</i></p> <p>I continually now wonder whether it wouldn't have been wiser to transplant her much earlier. And it's the one thing that I would ask, that they look at and study- because it seems to me almost like a black art. How do you know when she needs a transplant? <i>(Mother, 13-17y, transplant, Canada)</i></p> <p>They've been so upfront and honest with it. I'm so thankful that my GP listened to me and didn't question it or didn't blame me. <i>(Mother, 8-12y, CKD, Australia)</i></p>
Identifying opportunities for control and inclusion	<p>I think now we have become quite vocal in what we want. Especially with immunosuppression. We have seen the effects on [our son], so sometimes it is a bit of a fight with the doctor. <i>(Mother, 8-12y, transplant, Australia)</i></p> <p>He's got another biopsy soon. And I'm thinking why are we having another one? And they're like 'just to see where we are'? And I'm thinking, is this really necessary? Does he really need it? <i>(Mother, 13-17y, transplant, Australia)</i></p> <p>I started doing all my medications, I want it to get to the point where I don't need them to do anything. Not depend on my parents, or fixing the medications I need to take, or the dosages. <i>(Boy, 18-21y, transplant, USA)</i></p> <p>I tend to know a lot in general, like 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. <i>(Boy, 13-17y, transplant, Australia)</i></p> <p>It was very tiring for me to have dialysis and go to school, so I asked my mum to sign me up, so I started homeschool. <i>(Boy, 18-21y, transplant, USA)</i></p> <p>When I ask a question that I really want to know I feel good about it because then I'm aware and I know what is going on with my kidney. <i>(Girl, 13-17y, CKD, Australia)</i></p> <p>They give us choices and keep us well-informed the doctors have been pretty good with their explanations of the medicines. <i>(Mother, 8-12 y, CKD, Australia)</i></p>
Empowering participation in children	<p>The doctors did well with making sure she knew what medications she was taking, how much she was taking, what they were for. <i>(Mother, 13-17y, dialysis, US)</i></p> <p>I know my doctor so well, you can say anything and he'll try make it happen. <i>(Girl, 13-17y, CKD, Australia)</i></p> <p>They [doctors] understand. <i>(Boy, 13-17y, transplant, Australia)</i></p> <p>I'm just worried 'cause you're like, at the moment it's in your mum and dad's hands, when you get older you've got to take it into your own hands, got to know about the medications and stuff. <i>(Boy, 13-17y, transplant, Australia)</i></p>
<b>Striving to assert own priorities</b>	
Negotiating broader life impacts	<p>I'm thinking broader, more about their ability to live independently, be an adult. 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. <i>(Mother, 13-17y, transplant, Canada)</i></p> <p>We've spent most of the time in hospital since then, and it's like you know [he is] missing out on his school, his friends. <i>(Mother, 13-17y, dialysis, Australia)</i></p> <p>The transplant surgeons were insisting that he should have his bladder augmented and he'd have to be catheterized for life and I said tell me why we are writing this off before it's had a chance to prove itself? And eventually we sourced an interim solution and subsequently he pees normally. <i>(Mother, 13-17y, transplant, Australia)</i></p> <p>They're only looking at it from a medical scientific outlook, parents care and love, doctors don't care and love, it's a job. <i>(Mother, 13-17y, CKD, Australia)</i></p> <p>Medication can make your kidney last longer. But is that a good longer? How are you surviving that longer? Are you in pain all the time? Are you in discomfort? You have a transplant 2 years early, but you've grown, you've played, you have enjoyed your life. You aren't in hospital all the time... So quality of life, not just how old you are going to get, but are they experiencing life and not just stuck in a hospital bed. <i>(Mother, 8-12y, transplant, Australia)</i></p> <p>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. <i>(Girl, 13-17y, transplant, US)</i></p>
Choosing to defer decisional burden	<p>They know what they're doing, I feel really comfortable with that. <i>(Mother, 13-17y, transplant, Canada)</i></p> <p>He's been brilliant, and he's always, ultimately, she's your child, it's her body, and he has said that. But there's times when you don't want the control, you don't want to have to make that decision, and you have to push it back onto them. <i>(Mother, 8-12y, CKD, Australia)</i></p> <p>They were really good at explaining things to us. It was scary, but at least we knew that it could be taken care of. <i>(Mother, 13-17y, dialysis, US)</i></p> <p>Doctors should have that reassurance, like "it'll be okay." <i>(Boy, 13-17y, CKD, Canada)</i></p>

	I don't talk to doctors a lot. I just sit there and let their mum talk. Well I don't like talking to males to start with. <i>(Girl, 13-17y, dialysis, Australia)</i> [I prefer to see doctors with my parents] because they know more stuff than I do. They know more of the terms. <i>(Girl, 8-12y, transplant, US)</i>
Overprotected and overruled	There are some sports that I'm not allowed to do at all, for the rest of my life. That I can get. But there's other sports I want to do, like hockey, where the padding is over where the kidney is. I love it. So I'm technically allowed to do it, but my parents won't let me do it. <i>(Boy, 13-17y, transplant, Australia)</i> I feel like that can be stressful at home, because your parents are protective - "Hey, have you taken your medication?" "Are you sure?" <i>(Boy, 13-17y, CKD, US)</i> My mum and my granny are so like on top of me. Sometimes in a good way sometimes in a bad way because it gets really annoying. <i>(Girl, 13-17y, CKD, Australia)</i> My mom is super protective. My mom isn't worried about my meds, but she's worried about the people, the food. <i>(Girl, 18-21y, transplant, US)</i>
Struggling to voice own preferences	I had to do something like this for my psychologist because I didn't take my tablets because they made me sick. We had to write a whole list down of what was important and what was not. ...I didn't take my tablets because they made me sick... Oh they are disgusting! I took a sip and I threw up. They said if I didn't drink it I wouldn't be able to eat. I still ate. But I didn't drink it.... <i>(Girl, 13-17y, dialysis, Australia)</i> I was very sad, because my parents didn't want me to have a quinceañera because they were worried that when I was having the time of my life, I might get a call, like, "We need you to come on home, we have a kidney for you". <i>(Girl, 13-17y, transplant, US)</i> Medical stuff, not social stuff. They [parents] don't understand. <i>(Girl, 13-17y, CKD, Australia)</i> I wish I could see my kidney. I don't ask because I don't want to seem stupid. <i>(Boy, 13-17y, dialysis, US)</i> Having a child and then passing it on to them. That worries me. I haven't really spoken to people about having children. That can wait. <i>(Girl, 13-17y, CKD, Australia)</i> Sometimes I want to ask but I normally don't ask because my parents will speak to them. And I get too shy to ask. <i>(Girl, 8-12y, CKD, Australia)</i> Some of the time it's because I'm shy to ask. Or if it is a really big question I'm like worried to ask. <i>(Girl, 13-17y, CKD, Australia)</i>
<b>Managing child's involvement</b>	
Respecting child's expertise	We talk about it, and if I don't agree with her I will overrule her, but she is the one that makes the decision, because it's her body. <i>(Mother, 13-17y, dialysis, Australia)</i> Two years later [in remission] he got a cold and he knew the achiness of his lower back, he felt his body, you know, how it felt then [at previous diagnosis of nephrotic syndrome], he knew it was the same sort of thing. <i>(Mother, 13-17y, CKD, Australia)</i> She's proud of her scars, she wears them with honour... So it's a battle that she's won, or she's winning. <i>(Mother, 13-17y, dialysis, Australia)</i> It's his body, even though it affects the whole family, but he's the one that has to come to terms with what he has for the rest of his life. <i>(Mother, 13-17y, dialysis, Australia)</i> [My daughter] gets most of the say. I allow [her] to decide what she wants to do, because she's the one that's gotta go through it, not me. You know, I've gotta be there with her, every step of the way, but I believe the decision's up to [her]. <i>(Mother, 13-17y, CKD, Australia)</i> Yeah, with our daughter the big trouble now would be that she's 11 years old, she doesn't bother, she still thinks that she doesn't really have that understanding <i>(Father, 8-12y, CKD, Australia)</i>
Attributing 'risky' behaviors to rebellion	<i>Mother 1:</i> For me it's her taking her tablets. It's the thing keeping her well, and alive, and it's, it's a struggle when she misses several days, and all you see is the blood pressure go straight back up. <i>Mother 2:</i> How old is she? <i>Mother 1:</i> Fourteen. <i>Mother 2:</i> Fourteen, teenagers! <i>(Mothers, 13-17y, dialysis/CKD, Australia)</i> We also get the teenage rebellious I don't want to take my pills today. I don't want to do it anymore. <i>(Mother, 13-17y, transplant, Australia)</i> We threaten her all the time, she's 15, she's at the age when she's tired of cath and all that. She does everything that all the kids around her do. But she has issues, and that's something we can't make her understand. It's a hard age. <i>(Father, 13-17y, dialysis, US)</i> She did sneak off to a party. She did have a drink. We found out through Facebook and we badgered her about her choices...I said you need to know your choices and you need to make the right ones. <i>(Grandmother, 13-17y, CKD, Australia)</i>
Protecting the child from illness burden	I went back and forth on that, in terms of letting [my daughter] know how serious it is, or just let her be a kid and me worry about it. Because I tell her all the time "I got this, I'll do all the worrying, you go and be a kid." <i>(Mother, 13-17y, transplant, US)</i> I tried to keep my son in the dark for as long as I can. <i>(Mother, 13-17y, CKD, US)</i> 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 three months I thought, I better check myself as well, and remind myself well hang on, he's still got to be a child. I'm not going to let him sit there and ponder or worry about what's wrong with him. <i>(Mother, 8-12y, CKD, Australia)</i>

US: United States

## Figure Legends

### Figure 1. Thematic Schema

The uncertainty of prognosis and management of CKD served to compound the already difficult nature of decision-making for parents and children. Some felt they were not given adequate preparation and explanations of treatments (e.g. transplant and immunosuppression), and both parents and children wanted more information about their disease and potential treatments communicated in plain language to inform their decision-making. The lack of transparent information led parents to believe clinicians were withholding information about their child's prognosis. Similarly, children felt their parents were censoring information about their CKD. Parents were further disempowered when they were forced to relinquish part of their caring responsibilities due to their lack of technical expertise (e.g. home dialysis).

Over time parents began to recognize their 'gut' instincts added valuable and complementary information to support decision about their child's treatment, and they developed confidence to challenge clinicians, and subsequently they felt more involved and in control of their child's health. As children grew older, they too looked for opportunities to be involved in their care and were able to do so when supported by parents and clinicians.

Once parents developed confidence in their own expertise they were able to assert their priorities to ensure clinicians considered the broader impact treatments would have on quality of life. While some remained sceptical from feeling uninformed, others developed trusting relationships with clinicians who they sometimes relied on to ease their decisional burden when decisions were too difficult. While children were also concerned about the impact decisions would have on their quality of life, their view of what was important often differed from their parents (e.g. ability to play sport). Their ability to assert these preferences was limited by their interactions with parents and clinicians which made them feel that their priorities were not important.

Parents were then able to re-establish their role as protectors for their children. However, as their children developed and wanted more control, parents had to balance allowing decisional autonomy and trusting their child's expertise with the desire to protect their child from the burden of their disease as well as from potential risky behaviors. From the child's perspective, this limited their involvement and denied them opportunities to practice decision-making in preparation for adulthood.