

Perspectives of Clinicians on Shared Decision Making in Pediatric CKD: A Qualitative Study



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Rationale & Objective: Clinical decision-making priorities may differ among children, their parents, and their clinicians. This study describes clinicians' perspectives on shared decision making in pediatric chronic kidney disease (CKD) and identifies opportunities to improve shared decision making and care for children with CKD and their families.

Study Design: Semistructured interviews.

Setting & Participants: Fifty clinicians participated, including pediatric nephrologists, nurses, social workers, surgeons, dietitians, and psychologists involved in providing care to children with CKD. They worked at 18 hospitals and 4 university research departments across 11 countries (United States of America, Canada, Australia, People's Republic of China, United Kingdom, Germany, France, Italy, Lithuania, New Zealand, and Singapore).

Analytical Approach: Interview transcripts were analyzed thematically.

Results: We identified 4 themes: (1) striving to blend priorities (minimizing treatment burden, emphasizing clinical long-term risks, achieving common goals), (2) focusing on medical

responsibilities (carrying decisional burden and pressure of expectations, working within system constraints, ensuring safety is foremost concern), (3) collaborating to achieve better long-term outcomes (individualizing care, creating partnerships, encouraging ownership and participation in shared decision making, sensitive to parental distress), and (4) forming cumulative knowledge (balancing reassurance and realistic expectations, building understanding around treatment, harnessing motivation for long-term goals).

Limitations: Most clinicians were from high-income countries, so the transferability of the findings to other settings is uncertain.

Conclusions: Clinicians reported striving to minimize treatment burden and working with children and their families to manage their expectations and support their decision making. However, they are challenged with system constraints and sometimes felt the pressure of being responsible for the child's long-term outcomes. Further studies are needed to test whether support for shared decision making would promote strategies to establish and improve the quality of care for children with CKD.

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Children with chronic kidney disease (CKD) have an increased risk of mortality and impaired physical, social, psychological, and cognitive functioning that may impact their growth and developmental trajectories.¹⁻⁶ The treatment regimen can be complex, is associated with complications and side effects, and can interfere with the child's school, family, and social life. Shared decision making, defined as "an interactive process in which patients, families and physicians participate in all phases of the decision-making process and together arrive at a treatment plan to be implemented,"⁷ can improve a patient's knowledge, treatment adherence, satisfaction, and outcomes.⁷⁻¹¹ However, negotiating the conflicting priorities and establishing trust among the child, parent, and clinician can be difficult in pediatric CKD.^{7,8,12-15}

The lack of involvement of children and families in treatment decision making can cause fear, disengagement from health care, disempowerment, and decisional conflict, which can consequently jeopardize safety, quality of care, and outcomes for the children.^{7,9-11,16-19} When deciding about treatment efficacy, children with CKD

prioritize outcomes that threaten their sense of normality (eg, school or sport participation) such as fatigue and well-being; by contrast, clinicians give higher priority to hospitalization and mortality.^{20,21} Resolving such a mismatch in priorities and treatment goals is challenging and requires a sufficiently shared understanding of the expectations around the condition and its treatment(s).

This study describes clinician perspectives on shared decision making in CKD. Better strategies are needed to support the development of techniques and frameworks for shared decision making that address the priorities of patients, families, and clinicians^{7,22-24} with an ultimate goal of achieving better care and outcomes for children with CKD and their families.

Methods

Qualitative research methods are designed to generate insights about patients' priorities, values, and beliefs. Semistructured interviews can elicit in-depth insights about the individual priorities, values, and beliefs of the participants

PLAIN-LANGUAGE SUMMARY

Decision making about treatment and care for children with chronic kidney disease can be challenging because the priorities held by children may differ from those of their parents and clinicians. We conducted interviews with 50 clinicians from 11 countries. The clinicians tried to support shared decision making by blending priorities and collaborating with patients and families, and to help set realistic expectations about treatment. Although clinicians felt they held primary responsibility for the long-term health and safety of patients, they had to balance this with promoting the priorities of the children, including their ability to socialize, school attendance, and managing symptoms.

that explain their decisions and behaviors.²⁵⁻³¹ We followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) to report this study, which covers the research team, study design, and data analysis and reporting.³²

Participant Selection and Setting

English-speaking clinicians, including pediatric nephrologists, nurses, social workers, surgeons, dietitians, and psychologists with at least 1 year of experience providing care to children with CKD and their families were eligible to participate. Clinicians were identified through our collegial networks and invited by email. Participants could also nominate other colleagues to participate. We applied a purposive sampling strategy to ensure a diverse range of participant characteristics (eg, gender, age, years of experience). The University of Sydney provided ethics approval (2017/304). All participants provided signed informed consent before the interview.

Data Collection

The interview guide (Item S1) was developed based on literature and discussion among the investigator team.²¹ From June 2016 to March 2020, authors C.S.H. or A.T. (both female researchers who completed training in qualitative research) conducted 1 semistructured interview with each participant in person (at a venue preferred by the participant, eg, at conference centers or clinics), by phone, or by video conference using Zoom software. Field notes of the main concepts arising from the interviews were taken. We conducted interviews until we reached data saturation—that is, when no new concepts were raised after 3 consecutive interviews. The interviews were audio recorded and transcribed.

Data Analysis

The transcripts were imported into HyperRESEARCH software (version 4.0.3, developed by ResearchWare Inc). Using thematic analysis,²⁷ author J.K. coded line-by-line

all meaningful segments of text relating to communication or shared decision making in the transcripts to inductively identify concepts, which were grouped into initial themes and subthemes. We identified patterns and links among themes to develop a thematic schema. To ensure the themes captured the breadth and depth of the data, these were discussed with A.T., C.S.H., and E.H. as a group, who also read the transcripts (investigator triangulation). The preliminary findings were sent to all participants for feedback to ensure that the results reflected the full range and depth of the data.

Results

Study Participants

Of the 73 invited participants, 50 (68%) from 22 centers across 11 countries participated (Table 1). Nonparticipation was due to refusal, illness, or inability to schedule an interview after 3 attempts. The 50 participants included pediatric nephrologists (n = 32), nurses (n = 8), and allied health professionals (n = 10). Thirty-one (62%) were women and 26 (53%) of the participants had more than 10 years of clinical experience in nephrology. The average duration of the interviews was 21 minutes, 42 (84%) were conducted in person and 8 (16%) were conducted by phone or video conference (eg, Zoom).

Overview of Themes

We identified 4 themes: (1) striving to blend priorities, (2) focusing on medical responsibilities, (3) collaborating to achieve better long-term outcomes supporting shared decision making, and (4) forming cumulative knowledge. Each theme is expounded by subthemes, which are described here with supporting quotations provided in Box 1. A thematic schema (Fig 1) illustrates how the themes relate to each other.

Striving to Blend Priorities

Minimizing Treatment Burden

In making treatment decisions or recommendations, the participants considered that some interventions (eg, kidney biopsy, growth hormone) might “not be worth it” if they imposed an excessive burden on children and families. Some were conscious that children wanted freedom, independence, and time away from medical settings where blood tests, dialysis sessions, or biopsies were performed; they sought to ensure children were “able to live as normal life as possible.” To minimize the treatment burden, the participants responded to the needs of their patients and their families, for example, by rescheduling bloodwork or dialysis so children would not miss out on school and time with family: “There are times where we have to look at clinical outcomes as far as blood pressure control, hospitalization versus they [patients] just want to go home and be with their family on their brother’s birthday.” Sometimes they arranged for the bloodwork to be done in

Table 1. Participant Characteristics

| Characteristic | Value |
|--|----------|
| Female sex | 31 (62%) |
| Age group ^a | |
| 20-29 y | 1 (2%) |
| 30-39 y | 14 (29%) |
| 40-49 y | 21 (43%) |
| 50-59 y | 7 (14%) |
| 60+ y | 6 (12%) |
| Duration of clinical experience in nephrology ^a | |
| <10 y | 23 (47%) |
| 11-20 y | 13 (27%) |
| 21-30 y | 5 (10%) |
| 30+ y | 8 (16%) |
| Health professional role | |
| Pediatric nephrologist | 32 (64%) |
| Nurse | 8 (16%) |
| Social worker | 3 (6%) |
| Surgeon | 3 (6%) |
| Dietician | 2 (4%) |
| Nephrologist ^b | 1 (2%) |
| Psychologist | 1 (2%) |
| Country | |
| United States | 24 (48%) |
| Canada | 8 (16%) |
| Australia | 5 (10%) |
| People's Republic of China | 3 (6%) |
| United Kingdom | 2 (4%) |
| Germany | 2 (4%) |
| Other ^c | 5 (10%) |
| No. of patients on hemodialysis ^d | |
| 1-10 | 18 (36%) |
| 11-30 | 7 (14%) |
| 31-50 | 21 (42%) |
| Not applicable | 4 (8%) |
| No. of patients on peritoneal dialysis ^d | |
| 1-10 | 15 (30%) |
| 11-20 | 5 (10%) |
| 21-30 | 23 (46%) |
| 50+ | 3 (6%) |
| Not applicable | 4 (8%) |
| No. of patients with a transplant ^d | |
| 1-20 | 5 (10%) |
| 21-40 | 10 (20%) |
| 41-50 | 4 (8%) |
| 50+ | 28 (56%) |
| Not applicable | 3 (6%) |

N = 50.

^aOne data point missing (n = 49).^bAdult nephrologist with research interest in young adults.^cFrance, Italy, Lithuania, New Zealand, and Singapore.^dNumber of patients they have in care.

outpatient clinics so it would cost less time to travel (especially for patients living in rural/remote areas).

Emphasizing Clinical Long-term Risks

The participants gave high priority to long-term medical outcomes but recognized this may not directly impact the

child's "everyday life ... I try to tell them about cardiovascular mobility, but they are not interested in 25 years down the line; for them the key outcome has more to do with their daily life and having a normal life as opposed to the numbers." Clinicians felt responsible for focusing on clinical parameters and tried to convey their importance to patients because these are less visible to families and are important when weighing treatment decisions. Some noticed that older adolescents did consider their future: "Older kids understand the importance of looking after their kidney and those long-term outcomes." Initiating conversations about long-term risks and "concerns about death and dying" could be difficult; they observed that patients and parents were reluctant to discuss these topics.

Achieving Common Goals

Participants believed that patients, caregivers, and clinicians should work to formulate and establish shared goals: "We recognize what actually we are looking for is a better life for our patients." They collaborated with patients and family members to help them achieve goals, including participating in school, sport activities, and family activities and events.

Focusing on Medical Responsibilities

Carrying Decisional Burden and Pressure of Expectations

The participants believed that sometimes the clinical information needed to make a treatment decision may not be understood by patients or their families. Conversely, some nephrologists felt that families expected them to "know all the answers." In some cases, the decision was too complex or urgent—for example, placing a catheter in an acute setting or immediately commencing dialysis based on blood tests (eg, hyperkalemia). Some felt they were "the bad guy" when having to make decisions against the patient's or family's preference. One nephrologist reported being accused by parents of "wanting to keep a patient in hospital for no reason." It could be difficult to explain to parents the need for hospitalization, particularly when the child appeared well. Some of the participants viewed their role was to "guide the child in helping them to make decisions as well."

Working Within System Constraints

Resource and time limitations were a constant frustration for clinicians, and some felt they had insufficient time to address important concerns including mental health: "You've got 15-minute appointments, and you've got to cover all the CKD stuff, that doesn't leave you with much time to look at the psychological side." They were forced to work in "a system that has to work for the whole patient group," which conflicted with taking "in consideration what patients want."

Ensuring Safety Is the Foremost Concern

The participants strived to ensure patient safety, and sometimes they had to make urgent treatment decisions to avert life-threatening consequences: "[If] the chemical markers

Box 1. Selected Participant Quotations for Each Theme**Striving to Blend Priorities***Minimizing treatment burden*

"Some kids are so anxious about the injections [growth hormone] you just accept they will not reach full potential growth and stop giving them." (Pediatric nephrologist, Canada)

"We'll say, 'Come and get your bloodwork done,' but they might just want to go to school and be normal. So we sometimes have to adapt to their social situation." (Transplant coordinator, United States)

"When they tell me 'I need to go to a graduation today,' or 'I want to go on a family trip,' I would ask myself, 'Do they really need to have this procedure today or can we reschedule?'" (Pediatric nephrologist, United States)

Emphasizing clinical long-term risks

"A common scenario is where a child is experiencing side effects related to treatment, eg, immunosuppressive therapy, and they want to reduce the therapy. We know when it is reduced in such a way it actually does impact long-term survival. We have to talk with the patient about this trade off." (Pediatric nephrologist, Canada)

"I think it's very difficult for a child to oversee the long-term picture. They are not interested in bone health at the age of 40; we are looking at those things with a very different focus." (Nurse, Canada)

Achieving common goals

"In the end, we actually all want the same thing. It's just the way we think about them is slightly different. We tend to concentrate on numerical outcomes, but really in the end we are all looking for a better life for our patients." (Pediatric nephrologist, Australia)

"There shouldn't be a huge dissonance or difference between what our overall goals of care are. There may be differences in how to get there." (Pediatric nephrologist, United States)

Focusing on Medical Responsibilities*Carrying decisional burden and pressure of expectations*

"Yes, we are looking out for the best interest for the patients, but we also want to make sure we do the 'right thing.'" (Transplant coordinator, United States)

"If a decision can be made with the family, that's good. Sometimes there are very complex decisions or they have to be made fairly rapidly, in those cases we [doctors] make the decision for the patient." (Surgeon, United States)

"I often get the response, 'Well you're the doctor, I don't know,' when it comes to complicated things." (Nephrologist/researcher, United States)

Working within system constraints

"There is always some conflict because unfortunately health care is not luxuriously stacked and there are financial recourse limits that you need to stay within. And it is a system that has to work for the group." (Pediatric nephrologist, United States)

"During consultation you are spending time covering all the kidney stuff; you perhaps don't have time to address what they really want to talk about, what's high on the patient's agenda." (Pediatric nephrologist, United Kingdom)

Ensuring safety as foremost concern

"For PD you do need a supporting family who are able to commit themselves to do that; otherwise, it is not an option, even though it does provide a better quality of life." (Pediatric nephrologist, Canada)

"You sort of try to keep kids out of the hospital so they can do 'regular kids stuff.' This is obviously a priority to the parents as well. Unfortunately, sometimes you have to have people in the hospital to be able to do what we need to do." (Pediatric nephrologist, United States)

"We try to manage labs outside of the hospital. We'll, for example, first tell them to hydrate, and then have them repeat the bloodwork. When it's still abnormal, we do have to bring them into the hospital." (Transplant coordinator, United States).

"The family's priorities are always in the center, unless there's a safety issue that overrides it." (Surgeon, United States)

Collaborating to Achieve Better Long-Term Outcomes*Individualizing care*

"We present the options to families, and then the family is going to decide what they think are significant side effects. For me, a little hair growth wouldn't bother me. But for someone who's going to school with people who tease you, it's the whole world." (Pediatric nephrologist, Canada)

"If, for example, you have a teenager that's very active at school, that may be someone that prefers PD because then they don't have to miss out on that stuff. But then you might have another younger kid that relies on the parents more, and the parents are not comfortable with PD and prefer HD." (Psychologist, United States)

"Maybe you're not always choosing the ideal medically, but you're choosing something that they really prioritize." (Child life specialist, United States)

Creating partnerships

"I do try to make a point of speaking to the kids [rather] than just to the adults, and making sure they feel as though they are part of the clinical process." (Nurse, Canada)

(Continued)

Box 1 (Cont'd). Selected Participant Quotations for Each Theme

"I think it has to be a partnership, I really do. It shouldn't just be the patient's choice because we know medically what the patient needs. It goes both ways, but in the end the patients have their life to contend with. It's good to have everyone's perspective." (Dietitian, Canada)

"It's often a negotiation with the families, so we really need to work with the families and have good communication skills and build trust." (Transplant coordinator, United States)

Encouraging ownership and participation in decision making

"When you are looking at older adolescents, there is a shift; they start becoming more responsible for their own care. They understand the importance of organizing their care, getting prescriptions, etc. I feel then they start to realize how much that stuff will affect them." (Pediatric nephrologist, Canada)

"I actually try to ask the children if there are any issues that they particularly want to talk about to make sure they feel part of the process." (Nurse, Canada)

"It does really depend on the age of the kids and the relationship you have with them. Obviously when they are younger they aren't really going to participate very much. Older kids have a bigger ability to express their opinions. They get to say more on how things are going to go." (Nephrologist/researcher, Canada)

Sensitive to parental distress

"Sometimes the parents aren't compliant with the diet, but you tolerate it because you know in the end you need to work with the family. It can be hard to judge when to step in." (Pediatric nephrologist, Australia)

"I think we really have to keep in mind we're asking parents to do very invasive things. Sometimes parents would tell me 'Oops, I forgot.' But they didn't forget—it was just too hard for them." (Pediatric nephrologist, Canada)

"We ask parents to make sure their child adheres to the strict diet at every visit, but this can be very difficult. 'He goes to school, and I can't monitor what he eats at school or when he goes out with friends.'" (Dietitian, United States)

"I'm not sure we look at the parents enough. How many stay together? What does it do to the family, to their finances? Some have to take off work 3 times a week to take their kid to dialysis." (Surgeon, United States)

Forming Cumulative Knowledge*Balancing reassurance and realistic expectations*

"There's a large variation in what some families want and what some physicians want. Understanding of expectations can avoid those type of problems." (Pediatric nephrologist, United States)

"Sometimes there is a mismatch in expectations. Especially with a transplant. We try to convince patients the transplant is not a cure for end-stage disease but sort of a more efficient way to do dialysis and it is associated with better survival." (Pediatric nephrologist, United States)

"I do talk about life expectancy, but things might change. If you had asked me about life expectancy 20 years ago, I would have given a totally different number. We might have an artificial kidney or something like that." (Pediatric nephrologist, France)

Building understanding around treatment

"We all work together to try to educate the child in an age-appropriate language. The degree and detail of understanding grows as the child becomes older. So transplanting a kid at 3 years old, his understanding is a lot more limited compared to when he is 8 years old." (Pediatric nephrologist, United States)

"I really try to gauge their understanding of why they take the medicine. Do they understand what the medicines are doing?" (Child life specialist, United States)

"For younger children you should use illustrations as educational material—for example, when explaining CVD risk. We give children a picture and explain to them what is happening to their artery [and] same with a picture of their heart. We can talk to them and show them 'this is your heart, and the walls of your heart are about 2 times as thick as it should be.'" (Pediatric nephrologist, Germany)

"If we show them the growth curves—how they are doing in terms of growth compared to 'normal'—that is something that they can understand better so they can understand why it's important to take the growth hormone every day. And so that is a matter of education." (Pediatric nephrologist, France)

Harnessing motivation for long-term goals

"I talk about why it is important [to take their medication] and that if they don't take it, 'I won't know, but in a few months your body will know. Your body will reject, and there won't be much we can do.' I am pretty straightforward with them about the possible consequences." (Pediatric nephrologist, United States)

"I would tell them they did a good job all week, and they can go ahead and have a treat on the weekend. Motivating them in a sense. We try our best to find what motivates that child." (Dietitian, United States)

Abbreviation: PD, peritoneal dialysis.

are all over the place and the kid is not compliant with their meds or the parents aren't compliant with the diet ... there is a potential for long-term harm, and we need to step up." One participant had to transfer a patient from peritoneal

dialysis to hemodialysis due to concerns about their ability to maintain hygiene practices: "You want to do what the family wants, but sometimes it's a no brainer. It becomes a safety issue."

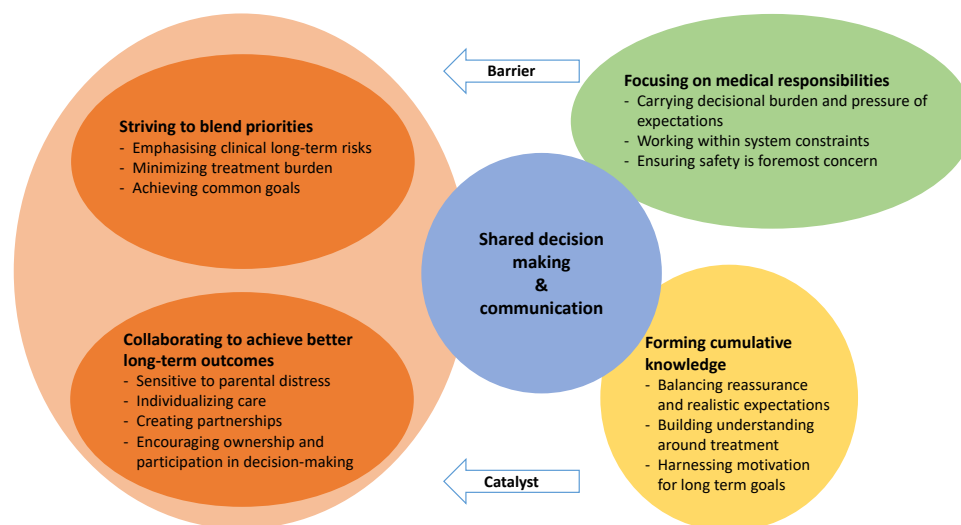


Figure 1. Thematic schema outlining the relationships between the themes and subthemes around shared decision making in child-hood chronic kidney disease. To support shared decision making in pediatric chronic kidney disease, clinicians reported setting common goals, minimizing treatment burden, creating partnerships, and encouraging children to be involved in the decision making. They strived to blend priorities and collaborate with the children and their families. Clinicians mentioned they encountered some barriers including working within system constraints (eg, time limits, financial limits) and having a perceived sole or primary responsibility for ensuring patient safety. They communicated with children and families about expectations, long-term goals, and their motivations, and sought to build understanding about the disease and treatment to enable children and families to take part in the decision-making process.

Collaborating to Achieve Better Long-term Outcomes

Individualizing Care

Participants wanted the best for the patient both medically and socially. Because “not everyone is the same,” some clinicians adjusted their usual recommendations about treatment modality and medications based on patient and parental preferences: “Decision making is mostly based on what patients really prioritize or provides a better quality of life.” They made decisions about medications in consideration of the impact on self-esteem and body image: “One of the medications has terrible side effects—hair growth, gum hypertrophy—and they’re all exterior physical changes. For a teenage boy or girl, they’re not going to take it. They’re not going to be compliant. So why would that be your first choice for them?”

Creating Partnerships

Participants believed partnership required them to “negotiate,” “compromise,” “meet in the middle,” and “align” with patients and their families, particularly because of the substantial lifestyle changes required: “We’re changing so many things. We’re changing the way they eat, we’re changing the way they drink, we’re changing the way they go to school, we’re changing the way they live their lives basically. We need them to cooperate in the long term.” Some nurses recognized that judging or reprimanding a child for (eg, not taking

medication, not attending appointments, or not following the diet) could diminish rapport and trust: “At no point am I judging. I want to find out why they are not being compliant so we can fix it.”

Encouraging Ownership and Participation in Shared Decision Making

The participants sought to involve children in decision making, particularly for older children: “I try and speak to the kids rather than just to the adults and ask patients what is important to them.” Some remarked that at times parents could find it difficult to “step away” to allow the child to make his or her own decisions. Some participants convened support groups for patients and found they were better able to communicate their concerns when surrounded by peers.

Sensitive to Parental Distress

Participants were concerned that parents were often put in an “impossible position ... we put parents in charge of doing really difficult and painful things to their children. Our expectations of parents are sometimes too high” (eg, gastronomy feeds/vomiting, peritoneal dialysis systems, growth hormone injections). The participants recognized that the severe burden on and distress for parents were often overlooked and felt that they “should protect the parents more often.” Some parents had to give up their jobs, relocate, or separate because of their child’s CKD.

Forming Cumulative Knowledge

Balancing Reassurance and Realistic Expectations

The participants felt the need to reassure parents, particularly of young children, about what to expect in the future: “Parents are often worried—will their child need surgery? Can he attend school in the future? It is important to provide some sort of reassurance.” Some recognized that parents could have high expectations such as about the outcomes of transplantation, and this could lead to disappointment: “Sometimes we push so hard for a transplant; when they finally get it, they think everything is okay.” Helping parents to establish realistic expectations and enable preparedness was expected to help the parents better cope with managing their child’s disease trajectory, which may include graft loss and a return to dialysis. They also addressed the potential costs of care with parents.

Building Understanding Around Treatment

The participants emphasized the need to educate patients so they could understand the need and reasons for their treatment: “It is quite time consuming, but it’s very important to make sure patients understand what is going on ... Explain procedures to them using a book, an iPad, or illustrations. Show them how a biopsy is done, step by step.” Others mentioned “there are not a lot of materials available for younger kids to educate them.” Some tested the knowledge of their patients and asked what a medication is for, what their kidney does, or asked them to explain their condition in their own words. With younger patients, the participants directed education to the parents: “I don’t think we are doing a really doing job of sitting down with them [patient] and re-explaining when they are old enough to understand.” The explanation should be “developmentally appropriate” each time but evolve with maturity. Some noted that providing information about treatment encouraged and improved adherence to medications: “When you understand why you are taking medicine, you tend to take them.”

Harnessing Motivation for Long-term Goals

The participants had to identify the patient’s individual motivations for treatment. Some nurses and social workers mentioned “we often spent more time with the patients [compared with doctors]. We can find out what motivates a child to, for example, take their medicine or have their blood tests done.” Some participants mentioned that some children who received a kidney transplant but did not have experience with dialysis tended to be less motivated to adhere to treatment after transplant. Also when it was not possible to visually track progress when there was “no direct result” such as with growth hormones and immunosuppressants, the patients tended to be less motivated. Motivating kidney transplant recipients was more challenging than children receiving dialysis; the participants explained, “With a transplant you feel fine, and you forget

about it [medication]. When you are on dialysis, there is a constant reminder that, in order to have a better quality of life, you need to take your meds and maintain your diet.”

Discussion

In this study, we found that clinicians involved in the care of children with CKD reported striving to support shared decision making, minimize treatment burden, and negotiate different priorities to achieve the goals and reduce the burden for patients while at the same time they feel responsible for the child’s safety, health outcomes, and development. They endeavor to build knowledge in patients and families by setting realistic expectations and explaining medical treatment and procedures, and to harness motivation among patients for treatment to achieve long-term health goals such as cardiovascular health. Some experience the pressure of expectations and of having to make the “right” medical decision, and they feel frustrated at working within a resource-constrained system, which can limit their capacity to communicate and address critical concerns including mental health. The participants highlighted some unique considerations that are specific to the care of children and adolescents. For children with CKD, risks such as the long-term impacts of immunosuppression in adulthood need to be considered in decision making. Children with CKD are often unwell and require long-term invasive treatment (such as dialysis), so school attendance and socializing with friends may be a stronger priority in this population.³³ Also, in the context of pediatric CKD the parental burden may be more intense and pronounced, which can add to the complexity of care.

Most of the findings were broadly consistent across the participants. However, we noted some differences by geographic location and discipline. Some participants worked with patients from rural and remote areas, so they had to consider the long distances to urban hospitals for treatment (eg, by arranging bloodwork to be done in outpatient clinics). Nurses or social workers felt they spent more time with the patients compared with their nephrologists, and they felt they had a stronger connection and understanding of the families’ barriers and motivations for treatment (eg, attending appointments and taking medication).

A recent study on children’s and parental perspectives on shared decision making and communication in children with CKD found that parents value partnership with clinicians and do consider the long-term and quality of life implications of their child’s illness. Children with CKD want more involvement in treatment decision making, but they are limited by vulnerability, fear, and uncertainty.³⁴ Our findings highlight that clinicians also value partnership with parents and patients, and they emphasize the need to encourage ownership and participation in shared decision making. Also they feel children with CKD and their parents should be informed and educated about the

long-term effects of treatment and should have realistic expectations about the child's prognosis and treatment, including potential risks after kidney transplantation.

This study was multinational and provides in-depth insights obtained from the perspectives of a reasonably diverse group of clinicians working with children with CKD. We achieved data saturation after 50 interviews, and through investigator triangulation we verified that the themes represented the breadth and depth of the data. However, there are some potential limitations. Most of the clinicians were from high-income countries, thus it is uncertain whether the findings are transferable to other populations and settings. Also, the majority of the participants were physicians. Although clinicians likely experienced different types of medical education across different countries and centers—and therefore had varying degrees of exposure to shared decision making during their training—our findings show the themes were consistent and relevant across settings. There may be important cultural differences between Western countries and non-Western countries in medical approach because there may be differences in communication styles.

Based on our research, we have several suggestions for practice and future research. Interventions that promote shared decision making, such as decision aids, improve not only patient involvement in the shared decision-making process but also both physicians' and patients' satisfaction with the consultation. These decision aids are being used more and more often in varied disciplines, but they have seen limited use in nephrology and even more limited in pediatrics.³⁵⁻³⁸ In our study, some clinicians conceptualized shared decision making as eliciting patient preferences and priorities in an effort to arrive at a consensus-based decision. We suggest training for clinicians in shared decision making and in establishing partnerships in care and decision making.

Novel tools or mechanisms, in child-friendly formats, that enable patients to express their treatment preferences, symptoms, or lifestyle concerns—including the use of online platforms or mobile applications—may be potentially useful to support communication. There is also a need for improved support and resources to expand clinicians' capacities to comprehensively address and manage other critical issues, including mental health, academic and social challenges, treatment adherence, and parental burden (mental health, practical help). Multidisciplinary clinic and referral pathways involving psychologists and social workers are needed.

A systematic review of interventions to support shared decision making in pediatrics concluded that decision coaching (ie, individualized, facilitated discussion to prepare the patient for future decision making^{18,39}) had modest beneficial effects on the process of shared decision making, the decisional alignment between parents and children, and the perception of participants that they had been adequately informed about

their options.¹⁸ We suggest that such interventions for clinicians could be evaluated in the context of pediatric CKD.

One randomized trial found that an intervention involving a facilitated critique of a 5-step framework, strategies, and prerecorded modeled role-play for clinicians improved confidence in facilitating shared decision making with patients.⁴⁰ Clinicians in our study emphasized the need for better patient education and health literacy for children to be empowered to become active decision-makers in their own care. A systematic review found that educational video games were effective in improving knowledge, self-management, and the relationship with clinicians as well as the mental health of young people with chronic conditions.^{41,42} Clinicians may benefit from the availability of novel educational resources focused on improving health literacy in children and their caregivers. Further research to assess the effectiveness of various strategies and interventions for communication, shared decision making, and education in the pediatric CKD population is needed. We suggest involving children and parents in the development, implementation, and evaluation of possible interventions.^{43,44}

Clinicians reported striving to minimize the treatment burden and collaborating with their patients to support shared decision making and to manage expectations. However, they also reported being challenged by system constraints that limit their ability to address critical issues including mental health. Sometimes they also feel pressure to be responsible for the child's medical and long-term outcomes. Further studies on shared decision-making interventions for improving quality of care for children with CKD are needed.

Supplementary Material

Supplementary File (PDF)

Item S1: Interview guide.

Article information

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References

- Gerson AC, Wentz A, Abraham AG, et al. Health-related quality of life of children with mild to moderate chronic kidney disease. *Pediatrics*. 2010;125(2):e349-e357.
- Tong A, Tjaden L, Howard K, Wong G, Morton R, Craig JC. Quality of life of adolescent kidney transplant recipients. *J Pediatr*. 2011;159(4):670-675. e672.
- Lande MB, Gerson AC, Hooper SR, et al. Casual blood pressure and neurocognitive function in children with chronic kidney disease: a report of the children with chronic kidney disease cohort study. *Clin J Am Soc Nephrol*. 2011;6(8):1831-1837.
- Haavisto A, Korkman M, Holmberg C, Jalanko H, Qvist E. Neuropsychological profile of children with kidney transplants. *Nephrol Dial Transplant*. 2011;27(6):2594-2601.
- Hooper SR, Gerson AC, Johnson RJ, et al. Neurocognitive, social-behavioral, and adaptive functioning in preschool children with mild to moderate kidney disease. *J Dev Behav Pediatr*. 2016;37(3):231.
- Thys K, Schwering KL, Siebelink M, et al. Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: a systematic review. *Transplant Int*. 2015;28(3):270-280.
- Adams RC, Levy SE. Shared decision-making and children with disabilities: pathways to consensus. *Pediatrics*. 2017;139(6):e20170956.
- Damm L, Leiss U, Habeler U, Ehrich J. Improving care through better communication: continuing the debate. *J Pediatr*. 2015;167(2):501-502.e505.
- Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010;126(2):306-314.
- Kelly MM, Hoonakker PL. Getting on the same page: opportunities to improve parent-provider communication. *Hosp Pediatr*. 2017;7(9):562-563.
- Lerret SM, Haglund KA, Johnson NL. Parents' perspectives on shared decision making for children with solid organ transplants. *J Pediatr Health Care*. 2016;30(4):374-380.
- Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs*. 2014;18(3):273-280.
- Coyne I, Harder M. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. *J Child Health Care*. 2011;15(4):312-319.
- Ruhe KM, Wangmo T, Badarau DO, Elger BS, Niggli F. Decision-making capacity of children and adolescents—suggestions for advancing the concept's implementation in pediatric healthcare. *Eur J Pediatr*. 2015;174(6):775-782.
- Taub S. Learning to decide: involving children in their health care decisions. *Virtual Mentor*. 2003;5(8):255-256.
- Stacey D, Légaré F, Pouliot S, Kryworuchko J, Dunn S. Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. *Patient Educ Couns*. 2010;80(2):164-172.
- Stebbing C, Wong IC, Kaushal R, Jaffe A. The role of communication in paediatric drug safety. *Arch Dis Child*. 2007;92(5):440-445.
- Feenstra B, Boland L, Lawson ML, et al. Interventions to support children's engagement in health-related decisions: a systematic review. *BMC Pediatr*. 2014;14(1):109.
- Malone H, Biggar S, Javadpour S, Edworthy Z, Sheaf G, Coyne I. Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis. *Cochrane Database Syst Rev*. 2019;5(5):CD012578.
- Hanson CS, Gutman T, Craig JC, et al. Identifying important outcomes for young people with CKD and their caregivers: a nominal group technique study. *Am J Kidney Dis*. 2019;74(1):82-94.
- Hanson CS, Craig JC, Logeman C, et al. Establishing core outcome domains in pediatric kidney disease: report of the Standardized Outcomes in Nephrology—Children and Adolescents (SONG-KIDS) consensus workshops. *Kidney Int*. 2020;98(3):553-565.
- Gabe J, Olumide G, Bury M. "It takes three to tango": a framework for understanding patient partnership in paediatric clinics. *Soc Sci Med*. 2004;59(5):1071-1079.

23. Park ES, Cho IY. Shared decision-making in the paediatric field: a literature review and concept analysis. *Scand J Caring Sci*. 2018;32(2):478-489.
24. Wyatt KD, List B, Brinkman WB, et al. Shared decision making in pediatrics: a systematic review and meta-analysis. *Acad Pediatr*. 2015;15(6):573-583.
25. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA*. 2000;284(3):357-362.
26. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care B. What are the results and how do they help me care for my patients? Evidence-Based Medicine Working Group. *JAMA*. 2000;284(4):478-482.
27. Tong A, Winkelmayer WC, Craig JC. Qualitative research in CKD: an overview of methods and applications. *Am J Kidney Dis*. 2014;64(3):338-346.
28. Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *BMJ*. 2008;337.
29. Sellars M, Clayton JM, Morton RL, et al. An interview study of patient and caregiver perspectives on advance care planning in ESRD. *Am J Kidney Dis*. 2018;71(2):216-224.
30. Tong A, Brown MA, Winkelmayer WC, Craig JC, Jesudason S. Perspectives on pregnancy in women with CKD: a semi-structured interview study. *Am J Kidney Dis*. 2015;66(6):951-961.
31. Tong A, Henning P, Wong G, et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis*. 2013;61(3):375-384.
32. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
33. Kerklaan J, Hannan E, Hanson C, et al. Perspectives on life participation by young adults with chronic kidney disease: an interview study. *BMJ Open*. 2020;10(10):e037840.
34. Gutman T, Hanson CS, Bernays S, et al. Child and parental perspectives on communication and decision making in pediatric CKD: a focus group study. *Am J Kidney Dis*. 2018;72(4):547-559.
35. Towle A, Godolphin W, Grams G, LaMarre A. Putting informed and shared decision making into practice. *Health Expect*. 2006;9(4):321-332.
36. Elwyn G, Edwards A, Hood K, et al. Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. *Fam Pract*. 2004;21(4):337-346.
37. Brand PL, Stiggelbout AM. Effective follow-up consultations: the importance of patient-centered communication and shared decision making. *Paediatr Respir Rev*. 2013;14(4):224-228.
38. Fortnum D, Smolonogov T, Walker R, Kairaitis L, Pugh D. "My kidneys, my choice, decision aid": supporting shared decision making. *J Renal Care*. 2015;41(2):81-87.
39. Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Légaré F. Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision AIDS. *Med Decis Making*. 2012;32(3):E22-E33.
40. Hoffmann TC, Bennett S, Tomsett C, Del Mar C. Brief training of student clinicians in shared decision making: a single-blind randomized controlled trial. *J Gen Intern Med*. 2014;29(6):844-849.
41. Charlier N, Zupancic N, Fieuws S, Denhaerynck K, Zaman B, Moons P. Serious games for improving knowledge and self-management in young people with chronic conditions: a systematic review and meta-analysis. *J Am Med Inform Assoc*. 2016;23(1):230-239.
42. Tieffenberg J, Wood E, Alonso A, Tossutti M, Vicente M. A randomized field trial of ACINDES: a child-centered training model for children with chronic illnesses (asthma and epilepsy). *J Urban Health*. 2000;77(2):280-297.
43. Coyne I, O'Mathúna D, Gibson F, Shields L, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database Syst Rev*. 2013;6:CD008970.
44. Coyne I. Consultation with children in hospital: children, parents' and nurses' perspectives. *J Clin Nurs*. 2006;15(1):61-71.