Original Investigation

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Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study

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Background & Objectives: Effective communication and shared decision making improve quality of care and patient outcomes but can be particularly challenging in pediatric chronic disease because children depend on their parents and clinicians to manage complex health care 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 & Participants: Children with CKD (n = 34) and parents (n = 62) from 6 centers across 6 cities in Australia, Canada, and the United States participated in 16 focus groups.

Analytical Approach: Transcripts were analyzed thematically.

Results: We identified 4 themes: (1) disempowered by knowledge imbalance (unprepared and ill-informed, suspicion of censorship, and inadequacy as technicians), (2) recognizing own expertise (intuition and instinct unique to parental bond, emerging wisdom and confidence, identifying opportunities for control and inclusion, and empowering participation in children), (3) striving to assert own priorities (negotiating broader life impacts, choosing to defer decisional burden, overprotected and overruled, and struggling to voice own preferences), and (4) managing child's involvement (respecting child's expertise, attributing "risky" behaviors to rebellion, and 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 him or her to become a partner in decision making and prepare him or her for adulthood. Collaborative and informed decision making that addresses the priorities and concerns of both children and parents is needed.

Complete author and article information provided before references.

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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 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(p 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 health care, which can jeopardize safety, quality of care, and outcomes for children.[2-5,10-13] Despite this, evidence for 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 for mortality compared with the age-matched population and are at risk for serious comorbid conditions and impaired quality of life, which can limit their perceived capacity to participate in shared decision making.[3,17] Limited evidence exists for 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 to 21 years and children aged 8 to 21 years with stages 1 to 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 3 centers in Australia (n = 44), 2 centers in Canada (n = 16), and 1 center in the United States (n = 36). 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, sex, and socioeconomic status) and clinical (CKD stage and 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 older than 18 years. Parental consent and written assent were obtained for those younger than 18 years. Participants received $50 reimbursement (in their local currency) to cover travel costs. Ethics approval was provided by the institutional review boards 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 audiorecorded and transcribed verbatim. Question guides were developed from the literature and discussion with the investigators (Items S2 and S3). One investigator (CSH, AT, or TG) facilitated the group while a second investigator (AJ, LJ, AT, TG, or AR) took field notes.

Analysis

Transcripts were entered into HyperRESEARCH software to facilitate qualitative data analysis. A single individual (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 relationships among themes (Fig 1).

Results

Participant Characteristics

In total, 62 parents and 34 children participated in 16 focus groups. Participant characteristics are shown in Tables 1 and 2. Parents were aged 24 to 58 years and most were mothers (47 [76%]). Twenty-five (40%) parents had children who had CKD stages 1 to 5, 14 (23%) had children treated by dialysis, 22 (35%) had children with a kidney transplant, and 1 parent did not report the CKD stage of the child. Seven (11%) parents had a child with CKD who was younger than 8 years. Children ranged from 8 to 21 years (ie, 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 stages 1 to 5, 5 (15%) were treated by dialysis, and 12 (35%) had received a kidney transplant. Twenty-nine children had at least 1 parent who also participated in the study.

We identified 4 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 or child) and relationship context (within the triad). Selected quotations to support each theme are available in Box 1. Figure 1 shows the relationships among themes and subthemes.

Themes

Disempowered by Knowledge Imbalance

Unprepared and Ill-Informed. Uncertainty surrounding their child's prognosis meant that some parents felt inadequately warned about their child's need for treatment (eg, transplantation). Some believed they were given "false hope" and "unrealistic" expectations regarding medication side effects and surgery recovery, while others thought that they were "getting railroaded into things" (eg, 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 (eg, blood test 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 affect fertility and "what happens after" graft failure.

Suspicion of Censorship. Some parents speculated that clinicians withheld certain information (eg, 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 that they "didn't get told everything" about their CKD and some thought that 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