Patient, Parental, and Health Professional Perspectives on Growth in Children With CKD

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Rationale & Objective: Growth failure is a common problem among children with chronic kidney disease (CKD). Reduced height is associated with psychosocial burden, social stigma, and impaired quality of life. This study describes the aspects of growth impairment that are most impactful from the perspectives of children with CKD, their parents, and health professionals.

Study Design: Qualitative study.

Settings & Participants: 120 children with CKD (aged 8-21 years), 250 parents, and 445 health professionals from 53 countries who participated in 16 focus groups, 2 consensus workshops, and a Delphi survey.

Analytical Approach: A thematic analysis of all qualitative data concerning growth from the Standardized Outcomes in Nephrology–Children and Adolescents (SONG-Kids) initiative.

Results: We identified 5 themes: diminishing psychological well-being (compared to and judged by peers, tired of explaining to others, damaging self-esteem), constrained life participation and enjoyment (deprived of normal school experiences, excluded from sports or competing at a disadvantage, impaired quality of life in adulthood); grappling with impacts of symptoms and treatment (difficulty understanding short stature and accessing help, lack of appetite, uncertainty regarding bone pains, medication side effects, burden of growth hormone treatment); facilitating timely interventions and optimizing outcomes (early indicator of disease, assessing management, maximizing transplant outcomes, minimizing morbidity); and keeping growth and health priorities in perspective (quality of life and survival of utmost priority, achieved adequate height).

Limitations: Only English-speaking participants were included.

Conclusions: Impaired growth may diminish psychological well-being, self-esteem, and participation in daily activities for children with CKD. Balancing different treatments that can affect growth complicates decision making. These findings may inform the psychosocial support needed by children with CKD and their caregivers to address concerns about growth.

Visual Abstract online

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Growth failure affects many children with chronic kidney disease (CKD), and it is estimated that 40% of children with kidney failure requiring kidney replacement therapy are shorter than the third percentile of age- and sex-matched controls.[1,2] Reduced height is associated with a range of other complications of pediatric CKD, as well as impaired quality of life, psychological well-being, school performance, and social functioning.[3,4] Factors that may contribute to impaired growth in children with CKD include poor nutritional status,[3] metabolic abnormalities,[5] corticosteroid treatment,[6] suboptimal management of mineral and bone disorder,[5] and inadequate application of growth-enhancing strategies.

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Children requiring long-term dialysis have the worst growth outcomes followed by transplant recipients with poor graft function.[3,6,7] Nutritional supplementation is crucial to enhance growth in children with CKD, who often contend with poor appetite or altered taste, increased caloric requirements, strict dietary restrictions, and corticosteroid-induced growth suppression.[6,8] Recombinant human growth hormone (hGH) is also available for shorter children with CKD, but it is associated with some adverse effects and is underutilized or inaccessible in some countries.[1,5,9,10] Although recombinant hGH therapy can improve social and physical function, children with CKD and their families may decline recombinant hGH due to fear of injections, side effects such as muscle and joint pains, headaches, and benign intracranial hypertension, or prohibitive cost if coverage is unavailable.[11]

Achieving normal growth in children with CKD remains a challenge and requires consideration of the needs and preferences of the children with CKD and their caregivers.[1,6,12] This study elicited the important and specific issues on how growth impairment impacts children with CKD from the perspectives of the children, their caregivers, and health professionals. This may inform targeted strategies to address the priorities and concerns related to poor growth in children with CKD to support better patient-centered care and outcomes for children with CKD.

Methods

Context and Sources of Data

We used data from the Standardized Outcomes in Nephrology–Children and Adolescents (SONG-Kids)

PLAIN-LANGUAGE SUMMARY

Children with chronic kidney disease (CKD) are often much shorter than their peers and may experience poorer mental health and quality of life. To understand the specific important issues on how growth impairment affects these children, we collected qualitative data from the Standardized Outcomes in Nephrology–Children and Adolescents (SONG-Kids) initiative and analyzed perspectives on growth from patients, parents, and health professionals. These data revealed impaired psychological health, reduced enjoyment during school and sports, difficulty dealing with medication side effects and growth hormone treatment, and concerns related to tracking health status and kidney transplant outcomes. These findings may inform the psychosocial support needed by children with CKD and their caregivers to address concerns about growth and overall health.

initiative.[13] The primary aim of the SONG-Kids initiative was to establish consensus-based core outcomes to be reported consistently in trials of children with CKD.[13] The SONG-Kids core outcomes, identified as critically important by patients, caregivers, and health professionals, are life participation, survival, kidney function, and infection.[14] The seminal international Delphi survey established growth as one of the second tier outcomes, which was especially important to caregivers, to be reported in some trials in children with CKD.[14,15]

Secondary analysis of qualitative data is the use of existing data collected for another purpose to address a related or different question that had not been analyzed in the primary studies.[16,17] We conducted a secondary analysis of all the SONG-Kids qualitative data composed of 16 focus groups,[18] free text comments from a large and international Delphi survey,[15] and 2 consensus workshops.[14] In the nominal group technique study (n = 96), young people with CKD and their caregivers identified and ranked important outcomes to guide shared decision making (eg, survival, kidney function, growth, lifestyle restrictions) and explained their priorities in focus groups.[18] An online 2-round Delphi study (n = 557) in English, French, and Hindi languages asked patients, caregivers, and health professionals to rate the importance of outcome domains for trials in children with CKD on a 9-point Likert scale and to provide free text comments (growth was included in the survey).[15] Two international SONG-Kids consensus workshops (n = 162) were convened to elicit feedback from patients, caregivers, and health professionals on the potential core outcomes for trials in children with CKD.[14] Quotations related to growth were extracted from the datasets of the 3 aforementioned studies.

We analyzed the responses of child and adolescent patients (aged 8-21 years), caregivers, and health professionals that specifically pertained to growth. Any response that mentioned "growth," "height," "stature," "development," "short," "small," or other similar descriptors was included for analysis. The institution review boards that provided ethics approval are listed in Item S1.

Data Extraction and Analysis

Participant quotations were extracted from the original transcripts of the SONG-Kids focus groups and free text comments from the Delphi survey and the consensus workshops. Investigator J.G.W. initially read the transcripts, inductively identified concepts, and grouped similar concepts into themes and subthemes. Three investigators (A.J., S.A.C., and L.G.T.), who also read the transcripts, discussed and provided feedback on the preliminary analysis to ensure that the findings captured the full range and depth of data. J.G.W. conducted line-by-line coding of the transcripts in HyperRESEARCH version 4.5.1 (ResearchWare Inc) into the themes identified, and any revisions were made based on discussion with the research team. A comprehensive report was generated whereby all text coded to each theme was reviewed by A.J. and L.G.T. to ensure that the concepts were coded to the relevant themes.

We compared themes among patients, parents, and health professionals. A thematic schema was developed to illustrate the conceptual links between themes and subthemes.

Results

Participant characteristics are summarized in Table 1. In total, 34 patients and 62 caregivers from 14 countries participated in the nominal group technique study; 72 patients, 132 caregivers, and 353 health professionals from 48 countries participated in the Delphi survey; and 14 patients, 56 caregivers, and 92 health professionals from 7 countries took part in the consensus workshops. We identified 5 themes: diminishing psychological well-being, constraining life participation and enjoyment, grappling with impacts of symptoms and treatment, facilitating timely intervention and optimizing outcomes, and keeping growth and health priorities in perspective (Fig 1). Selected quotations for each theme are provided in Box 1.

Diminishing Psychological Well-being

Compared to and Judged by Peers

Children with CKD noted that they were much smaller "compared to all [their] other friends" and were bullied because of their short stature: "It's hard because of the disease and kids pick on you." Parents compared their child's growth with their siblings or classmates, describing the size difference as "very noticeable when standing with [their] peers," and sympathized with their child's exasperation of "being called short" (parent).

Table 1. Participant Characteristics

Characteristic	NGT N = 96[18]	Delphi N = 557[15]	Consensus Workshops N = 162[14]
Participant group			
Patient	34 (35%)	72 (13%)	14 (9%)
Parent/family member	62 (65%)	132 (24%)	56 (35%)
Health professional	0 (0)	353 (63%)	92 (57%)
Gender			
Male	32 (33%)	161 (29%)	49 (30%)
Female	64 (67%)	392 (70%)	77 (48%)
CKD stage (patient)			
1-4	17 (50%)	59 (30%)	NA
5	17 (50%)	145 (70%)	NA
Dialysis	5 (15%)	53 (25%)	NA
Transplant	12 (35%)	92 (45%)	NA
Patient age (y)	14 [12-16]	16 [13-18]	13 [10-16]
Patient age group			
8 to 18	31 (91%)	49 (68%)	9 (64%)
19 to 21	3 (9%)	16 (22%)	3 (21%)
Country			
Australia	24 (25%)	58 (10%)	65 (40%)
United States	23 (24%)	205 (37%)	60 (37%)
Canada	13 (14%)	42 (8%)	5 (3%)
United Kingdom	NA[a]	66 (12%)	5 (3%)
Singapore	0 (0)	36 (6%)	1 (1%)
India	NA[a]	17 (3%)[b]	1 (1%)
New Zealand	NA[a]	15 (3%)[b]	1 (1%)
Other	27 (28%)[c]	98 (18%)[d]	NA

Values for categorical variables are given as percentages; values for continuous variables are given as median [IQR]. Percentages do not always add up to 100% due to undisclosed responses (excluded). Abbreviations: CKD, chronic kidney disease; Delphi, a sequential, consensus-based survey method; NA, not available; NGT: Nominal Group Technique.

[a] India, England, and New Zealand are also included in “Other” for NGT.

[b] India and New Zealand are also included in “Other” for health professionals partaking in the Delphi survey.

[c] Other includes up to 11 countries: England, Ethiopia, Fiji, India, Kenya, Mexico, New Zealand, Pakistan, Poland, Somalia, and Vietnam.

[d] “Other” includes up to 43 countries: Argentina, Belgium, Bolivia, Brazil, China, Czech Republic, Egypt, France, Greece, India, Indonesia, Iraq, Italy, Jordan, Libyan Arab Jamahiriya, Lithuania, Malaysia, Mexico, Mongolia, Montenegro, Morocco, Myanmar, Netherlands, New Zealand, Norway, Pakistan, Peru, Philippines, Poland, Portugal, Romania, Russia, Saudi Arabia, Serbia, South Africa, Sri Lanka, Sudan, Sweden, Syrian Arab Republic, Thailand, Republic of Türkiye, Uruguay, and Venezuela.

Tired of Necessity to Explain to Others

Some children with CKD were tired of constantly explaining their short height, particularly when their friends did not understand they had CKD, which was often described as an “invisible” disease. Parents reported that their children were frequently asked, “Why are you so short?” or “why [they] looked so physically different” (parent). One parent recalled that the child had attempted to explain to friends that CKD caused him to “not grow at a regular rate”; however, the friends responded with “[kidney disease is] an old people’s thing” (parent).

Damaging Body Image and Self-esteem

Children wished they were taller and were upset at being mistaken for being younger than their actual age based on their appearance: “Everyone thinks I’m seven. I’m actually ten.” One parent commented that the child was “sad and depressed” when “everyone [else] suddenly [started] to grow,” and another parent reported the child was worried he was “never going to have a girlfriend” because of his short stature and “baby face.” Parents and health professionals were concerned that a child’s slower physical development relative to peers would “have a big impact on [his or her] mental health” (health professional). Health professionals believed the consequences of “short stature” included negative “body image” or worse “psychological health and well-being in young adults.”

Constraining Life Participation and Enjoyment

Deprived of Normality of School Experiences

Some children were upset that their small stature restricted their participation in the classroom, and they envied taller peers who were able to “see further away and sit at the back of the class.” Another patient “sometimes [didn’t] feel like other people” and felt “left out” at school because of shorter height.

Frustrated at Being Excluded From Sport

Some children were disappointed that they had to refrain from playing sports such as volleyball and basketball because they were “too short.” Some parents believed they needed to protect their child with CKD from potential

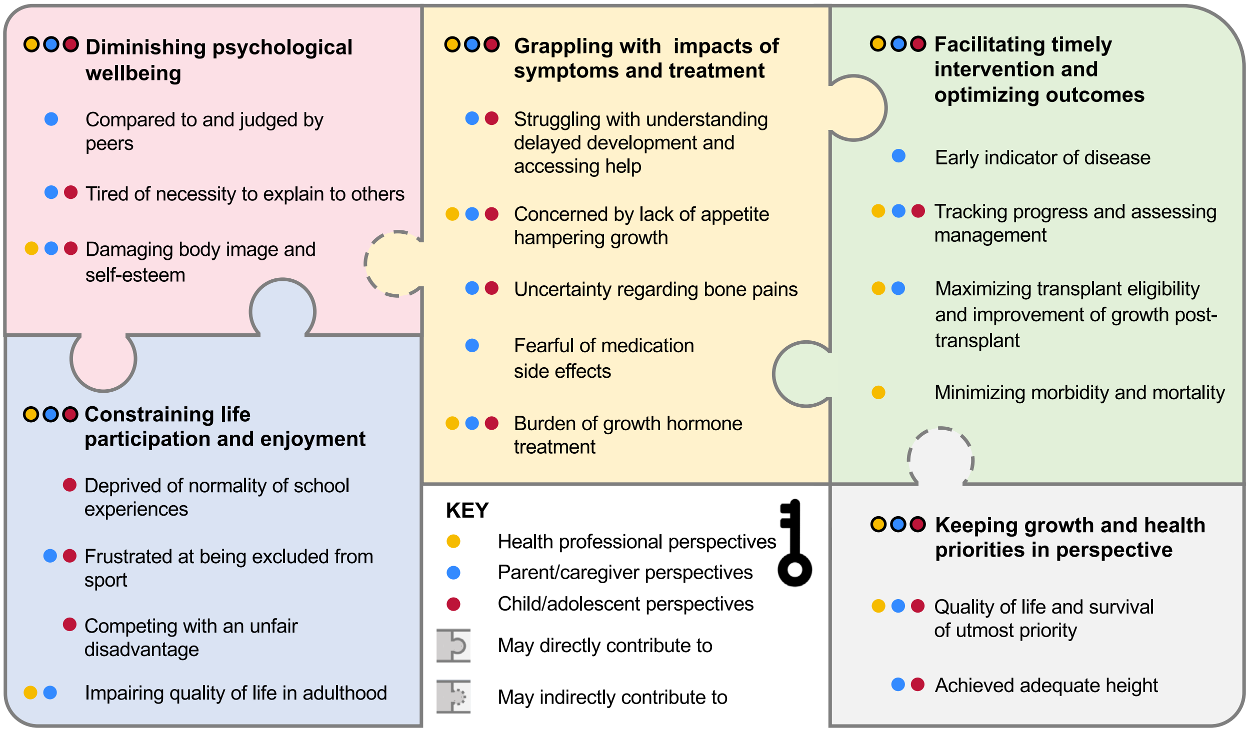

Figure 1. Thematic schema: perspectives on growth in chronic kidney disease.

physical injury. For example, they did not allow their child to "mess around with the cousins of the same age," worried they would "get hurt easier" due to their small size. One parent was concerned that "bigger kids don't realize … [they've] got to be careful" around children who are much smaller. However, this was also "upsetting" to parents because they knew their children wanted to join in the sport activities.

Competing With an Unfair Disadvantage

Children with CKD who participated in sports felt that their short height placed them at an unfair disadvantage, particularly when competing with their peers: "When I play basketball, I'm always racing people that are like, a lot taller than me, so it's harder." Another patient was annoyed that a smaller size meant that "when [we are] playing a game, [I'm] always … running behind," especially at "sport events."

Impairing Quality of Life in Adulthood

Health professionals expressed that height was a "major determinant of quality of life as an adult" and that short stature was a "common complaint … in survivors of pediatric-onset chronic kidney disease." One health professional recognized that the perceived importance of growth may increase toward the end of adolescence: "For young adults, short stature is related to poor quality of life … but in the middle school years … that's not [their] priority." Some health professionals viewed "growth [as] the number one item that most consumes parents and children, especially boys," especially because it enables them to "function normally in society as they grow older."

Grappling With Impacts of Symptoms and Treatments

Struggling With Understanding Delayed Development and Accessing Help

Some patients wished to better understand why "most people with kidney disease [are] usually short." Parents had unresolved questions about whether CKD placed their child on a delayed or shortened "track to puberty" or caused different rates of growth of tissues: "His bones have completely grown … but his tissues and muscles haven't caught up." Some parents were "disappointed that [they] were unable to access help for short stature" because it was not made available to them, or they sought clarification on complications associated with growth problems. Some parents of young children with CKD were anxious about delayed muscle growth, for example, in the "arm" or "stomach muscles," causing "gross motor delays" and an inability to crawl, stand, or walk.

Concerned by Lack of Appetite Hampering Growth

Some children felt annoyed by parents who urged them to "eat more so [they could] grow" (patient), particularly when they "[didn't] really like eating much" or "[didn't] feel hungry" (patient). Parents were troubled by their children's lack of appetite because it could hamper their

Box 1. Selected Quotations to Support Each Theme

Diminishing Psychological Well-being

- Compared to and judged by peers
    - o “[I am] not growing. And [my] friends look at [me] and are like … ‘You are short.’” (P)
    - o “My daughter has an identical twin, so maintaining the same growth was important to us.” (C)
    - o “I probably had growth at #1 [priority] because it’s really hard for her to put on weight and grow taller, so she’s probably 1 inch shorter than girls in her grade. That’s hard for her.” (C)
    - o “[He] is really small for his age. I brought 2 [more] kids into the family, and my [biological] kids are huge compared to him.” (C)
- Tired of necessity to explain to others
    - o “Some of them understand, but some of them, not so much.” (P)
    - o “I think for [him], when he was going through it all at school and explaining to his peers why he looked so physically different.” (C)
    - o “He’s in the classroom with kids who want to know … ‘Why does your stomach look like that? Why are you so short?’” (C)
    - o “He has to explain why he’s so short … ‘I have kidney disease, and I don’t grow at a regular rate.’ He’ll have to try to understand all the stuff that’s going on with him, and then try to explain it to other children who really don’t understand.” (C)
- Damaging body image and self-esteem
    - o “Both my parents are short, and the kidney failure made me even shorter. I would be about this much taller if I didn’t have kidney failure. And this is probably how tall I’ll be for the rest of my life.” (P)
    - o “My child is in middle school, [the] time in which everyone suddenly [starts] to grow. He felt very sad and depressed. He is getting treatment, and we are optimistic.” (C)
    - o “It is difficult for children, especially boys, to be short in stature. It is often hard on their self-esteem.” (H)
    - o “Body image is related to psychological health and well-being in young adults.” (H)

Constraining Life Participation and Enjoyment

- Deprived of normality of school experiences
    - o “If you are taller, it is easier to see further away and sit at the back of the class.” (P)
    - o “Physical activity, feeling normal, [and] school [are important to me]. Sometimes I don’t feel like other people, and I feel left out sometimes.” (P)
- Frustrated at being excluded from sport
    - o “They say, in volleyball and basketball, that I can’t play because I’m too short.” (P)
    - o “He can’t mess around with the cousins that are of the same age and my youngest son who’s the same age. It’s hard because he’s so small he’s going to get hurt easier, and it’s upsetting to me because he wants to be there.” (C)
    - o “Bigger kids don’t realize, ‘Hey, he’s so much smaller, you’ve got to be careful.’” (C)
- Competing with an unfair disadvantage
    - o “When I play basketball, I’m always racing people that are like, a lot taller than me, so it’s harder.” (P)
    - o “[At] school events like sport events, sometimes when I am playing a game I am always behind, running behind late to classes.” (P)
- Impairing quality of life in adulthood
    - o “He’s a lot shorter … and he looks so baby-faced. I think he’s worried that he’s never going to have a girlfriend.” (C)
    - o “[It is] vital to be able to progress through the norms of growth and development to be able to function normally in society as they grow older.” (H)
    - o “Short stature is the most common complaint and predictor of quality of life in survivors of pediatric-onset CKD.” (H)
    - o “For teenagers, for young adults, short stature is related to poor quality of life … but in the middle school years, that’s not your priority.” (H)

Grappling With Impacts of Symptoms and Treatment

- Struggling with understanding delayed development and accessing help
    - o “Most people with kidney problems are usually short. I don’t know why.” (P)
    - o “[We were] disappointed that we were unable to access help for short stature.” (C)
    - o “He doesn’t crawl. He’s 15 months old at the end of the month, and he doesn’t crawl yet. He doesn’t stand up properly and walk.” (C)
    - o “We know that children, young adults with CKD, reach final height and emotional maturity later. Everything’s kind of shifted a few years.” (H)
- Concerned by lack of appetite hampering growth
    - o “My parents are always talking about … me to eat more so I can grow because I don’t really like eating much. I just don’t feel hungry.” (P)
    - o “He’s actually not growing … he doesn’t want to eat, he doesn’t feel hungry, he skips breakfast.” (C)
    - o “[My child] is just on a feeding pump. So [my concerns] would be both developmental and eating.” (C)
    - o “Some don’t eat very well. It affects their growth, especially the babies; it’s a vicious cycle.” (H)

(Continued)

Box 1 (Cont'd). Selected Quotations to Support Each Theme

- Uncertainty regarding bone pains
  - o "When I grow, once when I felt the pain, I told my mum that I felt pain in my leg. And she said that maybe it's the growth, when I grow." (P)
  - o "My daughter always tells me she gets pins and needles. A lot in her thighs, or inner thighs … I'm not sure if that's [related to] growth." (C)
- Fearful of medication side effects
  - o "[It was] a relief when they finally can grow, [after being taken] off steroids." (C)
  - o "But with [mycophenolate] which they say is better for his kidney, he'll get the flu first and gastro and he'll have it like for a month which drains him and pushes him back on the growth. He doesn't grow when he is on [mycophenolate]." (C)
  - o "The prednisone fused her growth plates. And we didn't get there in time to actually do the growth hormone; it was already too far gone." (C)
- Burden of growth hormone treatment
  - o "I had to fight to get [growth hormone] for my son … I still don't know if it is worth the daily injections." (C)
  - o "Being short and not being able to access growth hormone has been difficult." (C)
  - o "We spend huge amounts on growth hormone, and [growth] is not in the [top priorities for] under 21s, or the people who've achieved final height. [They] don't seem to have any anxieties about growth." (H)

Facilitating Timely Intervention and Optimizing Outcomes

- Early indicator of disease
  - o "After I stopped breastfeeding him at 12 months, I noticed he didn't grow anymore." (C)
  - o "There's something wrong with her. And you'd go in and say, 'She's not growing.'" (C)
  - o "So when she was first not growing and peeing, … [I] said, 'You need to do something.'" (C)
- Tracking progress and assessing management
  - o "I like that growing thing, when they show me how much I grow." (P)
  - o "I am not that interested in [blood test results], but I know that I have to know. That is the truth of what is happening with my body. It tells me what is going on with my growth." (P)
  - o "When you come for your appointments, that's what you talk about. You talk about the growth; you talk about kidney function." (C)
  - o "[Growth] is an indication as to how well their kidney disease is managed. Dietetic input should be essential to work with the multidisciplinary team to improve this." (H)
  - o "Part of our treatment is to assess intake and adjust to promote growth. If [there are] no changes, then we consider growth hormone treatment." (H)
- Maximizing transplant eligibility and improvement of growth after transplant
  - o "[I'm] just waiting for him to be sized enough so the kidney would fit in him." (C)
  - o "He can't be on the transplant list. It's because he's got to be 22 pounds, and he's only 19." (C)
  - o "She dropped off below the tenth percentile, and after she was transplanted, she started growing." (C)
  - o "I would put growth [as a] lower [priority] now, but if it was pretransplant trying to get him to transplant, it might be higher." (C)
- Minimizing morbidity and mortality
  - o "[There is] increased morbidity and mortality associated with poor growth." (H)
  - o "Long-term outcomes associated with poor growth in pediatric patients are critically important." (H)
  - o "If a child is not growing well with CKD, you know there is something wrong, maybe infection, nutrition, or acidosis." (H)

Keeping Growth and Health Priorities in Perspective

- Quality of life and survival of utmost priority
  - o "My highest [priority] was kidney health because I think that's really important right now, and that's what's been important to me." (P)
  - o "Sport is [my] number 1 [priority]. Second is surgical recovery time because I've had a lot and then time spent at hospital." (P)
  - o "I can deal with if he is the shortest. I can deal with if he is the littlest kid. What's most important to me is that we do what's absolutely the best … for his transplant kidney to survive the longest, the least amount of dialysis in his life." (C)
  - o "He's followed the tenth percentile the whole time, and he's pretty short, and it hasn't bothered him too much." (C)
  - o "I think younger kids might say, 'Oh no I don't want an infection,' and someone who is older and short might say, 'Why didn't I get an infection?'" (H)
  - o "I was very much surprised at growth, which is an outcome parameter in many trials scoring so low. Apparently, it is not so important from the patient perspective … because it's almost the lowest, next to vision." (H)
- Achieved adequate height
  - o "I got sick when I was 16, so I didn't personally deal with these issues." (P)
  - o "I count myself lucky that [my CKD] started at 18 and I had my growth spurt [already]." (P)
  - o "Our son may be a little shorter than he should be, but his height is average." (C)

Abbreviations: C, caregiver; CKD, chronic kidney disease; H, health professional; P, patient.

growth: "He never gets hungry"; by their tendencies to skip meals: "He's actually not growing ... he skips breakfast"; and the requirements surrounding "feeding pumps." Similarly, health professionals also indicated that a lack of appetite in young children could hamper their growth, causing them and their appetites to remain small in a "vicious cycle" that could compromise their development.

Uncertainty Regarding Bone Pains

Young patients and their parents reported "pins and needles [in the child]" (parent) or "pain in [the] legs" (patient). Some parents attributed possible bone pain associated with CKD with typical growing pains while the children were unsure of why they were experiencing these sensations: "I didn't know that [pain in my legs] was [growing pains]!"

Fearful of Medication Side Effects

Some parents were concerned that immunosuppressants or corticosteroids could impact on their child's growth. One parent attributed a child's reduced appetite to immunosuppressive medication; another parent was anxious that mycophenolate would predispose the child to the "flu" or "gastro" and "push [my child] back on growth." One parent regretted that "prednisone [had] fused [my child's] growth plates" and that "[my child] didn't get there in time to actually do the growth hormone" because it was "already too far gone."

Burden of Growth Hormone Treatment

Some parents were distressed at "not being able to access growth hormone" for their child while others were concerned about the burden of injections and associated side effects: "I had to fight [for my child] to get [growth hormone injections] ... [but] I still don't know if it is worth the daily injections." Some children associated growth hormone therapy with needles, which scared some patients: "I don't like needles. I don't like crying." Some health professionals questioned whether the approach to growth hormone administration should be more targeted: "We spend huge amounts on growth hormone, and [yet growth is] not [a top priority] in the under-21s."

Facilitating Timely Intervention and Optimizing Outcomes

Early Indicator of Disease

Before the diagnosis of CKD, some parents became suspicious that their child might be unwell when they noticed that their child had stopped growing: "After I stopped breastfeeding him at 12 months, I noticed he didn't grow anymore." Some parents became distressed by their child's growth, and this was often a catalyst to seek medical attention, which led to the diagnosis of kidney disease: "She was first not growing [or] peeing ... [We] need to do something."

Tracking Progress and Assessing Management

Patients and their parents appreciated that health professionals regularly tracked their growth to evaluate their health: "I like that growing thing, when they show me how much I grow" (patient). Some parents expected conversations regarding their child's growth to be a routine component of check-ups that assessed their kidney function: "When you come for your appointments ... you talk about the growth; you talk about kidney function" (parent). Health professionals viewed growth as a surrogate measure or a "good overall parameter" to evaluate "how well [the patient's] kidney disease is managed." Health professionals relied on growth measurements to inform their clinical decisions such as recommending nutritional supplementation, advising "dietetic input," or "[considering] growth hormone treatment," and one health professional suggested the need for more accurate growth charts: "UK centile charts are now quite outdated." Some health professionals attributed growth as a direct consequence of CKD-related complications: "infection, nutrition, acidosis."

Maximizing Transplant Eligibility and Improvement of Growth After Transplant

Some parents of children requiring a transplant were concerned about meeting growth and weight eligibility criteria: "He can't be on the transplant list ... because he's got to be 22 pounds and he's only 19 [pounds]" (parent). Parents focused on maximizing their child's growth before transplant to optimize graft function. After transplantation, parents were reassured when "[my child's] growth really picked up," indicating the success of the kidney transplant: "[Her growth] is catching up since transplant" (parent).

Minimizing Morbidity and Mortality

Some health professionals perceived growth as a means of predicting and mitigating future "morbidity and mortality" and other "long-term outcomes associated with poor growth." These outcomes also included chronic anxiety and stress, impaired cognition, and depression.

Keeping Growth and Health Priorities in Perspective

Quality of Life and Survival of Utmost Priority

Some children and their parents prioritized reducing the "risk of infection" and hospitalization over growth "because I've had a lot [of surgeries and] time spent at hospital" (patient). Children explained that kidney health was of highest priority because "that's really important now... The lowest [priority] was growth" (patient). Some parents regarded growth to be a secondary concern—— "I can deal with [him being] the shortest"—and were instead focused on attaining "the best outcome for [my child's] transplant kidney to survive the longest" or the "least amount of dialysis in his life." Some clinicians were "very much surprised" that "growth [was] not higher marked" or "[didn't] even feature" in the first-tier outcomes despite being ranked "highest for health care providers." One health professional suggested that "younger kids" may be more scared of contracting an infection than having a stunted growth while "someone who is older and short" may think the opposite in hindsight.

Achieved Adequate Height

Some children and their parents felt that their height was reasonable and did not believe that CKD substantially impacted growth: "She's average height, 40th percentile, in spite of her [CKD]" (parent). Patients who were diagnosed with CKD during late adolescence had already experienced their pubertal growth spurt and were thus unconcerned about their height: "I got sick when I was 16, so I didn't personally deal with [growth] issues" (patient).

Discussion

Reduced growth in children with CKD may negatively impact their psychological well-being, self-esteem, and body image. Children with CKD felt limited in their ability to participate in and enjoy their daily activities because of their shorter height, and they believed they were disadvantaged in sports and other school experiences. Parents were worried about their child's delayed development and inadequate nutritional intake. Parents also expressed concerns about medications that could negatively impact growth such as corticosteroids and other immunosuppressants, and they experienced decisional uncertainty or reluctance to accept rhGH therapy. Children with CKD and parents recognized the importance of growth as a metric for monitoring kidney health and assessing the efficacy of disease management. Some children with CKD and parents had other overriding health priorities, such as optimizing kidney function and preventing hospitalization, or they had already achieved adequate height and thus viewed impaired growth to be less of a concern.

There were some apparent differences in perspectives on growth depending on the child's age at CKD diagnosis, and between health professionals and caregivers. For children whose CKD was diagnosed in infancy, the parents were concerned about growth in terms of developmental milestones and nutrition. School-age children sometimes felt alienated, envious of their taller peers, or feared their short stature would limit their school and sport experiences. Older adolescents with CKD reported that impaired growth caused them to have low self-esteem and threatened their ability to have romantic relationships. Those who did not experience growth difficulties, including children diagnosed after their pubertal growth spurt, tended to prioritize other areas of their health, including kidney function, immune system/infection, or symptoms (eg, fatigue and pain).

Parents expressed concerns about how their child with CKD differed in size to their siblings or classmates. They were concerned about methods of feeding their child—for example, whether to breastfeed or using an enteral pump—and they felt anxious about their child reaching the growth thresholds required to become eligible for a kidney transplant. Meanwhile, health professionals emphasized the association of poor growth with psychological well-being, increased morbidity and mortality, lower quality of life in adulthood, and reduced ability to function in society.

Growth failure has been consistently shown to be associated with lower quality of life in children with CKD across their life span,[4,19,20] reduced physical function,[21] poorer academic achievement,[22] lower levels of employment,[23] and fewer long-term partnerships.[23] Morever, in a 30-year follow-up study, short stature was independently associated with a reduced likelihood of having offspring as an adult.[24] Similar to our findings, a previous study found that parents of children with CKD worried that growth failure might impede their child's future health and prospects.[25] Our study provides data that may explain the association between reduced growth and quality of life in children with CKD. For example, school-aged children with CKD felt that their shorter stature placed them at a disadvantage, and they were consequently unable to enjoy group-based sports or play with peers. Adolescents with CKD felt self-conscious about delayed growth spurts in puberty and forming new relationships.

Growth is also a challenge in other chronic pediatric conditions such as cystic fibrosis,[26] skeletal dysplasias,[27] and inflammatory bowel disease.[28] Similar to our findings, children with cystic fibrosis have also expressed frustration about their shorter height and the additional exertion required in physical activities as well as confusion about their dietary needs[29] and disappointment in not achieving their desired physique in adolescence.[26] Children with skeletal dysplasia are frequently mistaken for being younger, are fed up with comments about their height, and feel hurt from being left out of activities due to their shorter stature.[27]

Our study highlights that children with CKD and their parents may also experience decisional uncertainty about immunosuppression because of its effect on growth and about treatments for growth including rhGH. Health professionals treating children with CKD may also struggle with their own beliefs regarding growth and the prescription of rhGH. For example, rhGH is less commonly prescribed for girls than for boys and for posttransplant patients due to concerns about triggering rejection episodes,[30] which may partially explain the lower adherence to national guidelines for rhGH prescription in some western European countries.[10]

Data from 3 extensive and methodologically diverse datasets, including 120 children with CKD, 250 caregivers, and 445 health professionals across 53 countries were analyzed to yield a broad spectrum of insights on perspectives regarding growth. However, we acknowledge some potential limitations of our study. First, most of the participants were from high-income English-speaking countries, and thus the transferability of the findings beyond these settings is uncertain. Our study was a secondary analysis, and detailed probes to elicit specific perspectives on growth may not have been used in all the original studies because their primary aim was not focused on growth.

Comprehensive psychological support and shared decision making are desired for a holistic approach to the management of pediatric CKD.[31] However, it remains an ongoing challenge to facilitate access to services to manage the psychological sequelae of impaired growth. There is a need to explicitly identify and address growth-related concerns, which may include poor body image, bullying, feelings of vulnerability, and being disadvantaged in social and academic opportunities. Multidisciplinary care—for example, involving dietitians and physiotherapists—may be desirable to address the challenges relating to diet and exercise in enhancing growth and development.[32,33] Although rhGH therapy has considerable benefits in most children with CKD of short stature, some families decline the treatment due to the additional needle burden or the side effects such as headaches and myalgias.[11] Strategies to address needle phobia may include deep-breathing exercises or group-based modified cognitive behavioral therapy, which has been demonstrated in children with diabetes who require insulin.[34,35] Informed decision making about timely administration of rhGH may be strengthened through the provision of education and counseling that could address the management of side effects (including treatment of joint pain, myalgias, and headaches), the options for dose-reduction, and the long-term benefits of rhGH therapy.[36] On the other hand, in many lower resource countries, rhGH is not available due to cost constraints, and the psychological impact on height needs to be studied in these settings.

We suggest that further research is needed to develop and evaluate psychological and educational interventions as well as multidisciplinary programs for children with CKD and their caregivers that address impaired growth. Dietary counseling in children with CKD[37] and other chronic conditions such as celiac disease[38] and diabetes[39] may have a role in improving adherence to nutritional guidelines, but there have been few clinical trials that formally have evaluated these interventions on growth outcomes. A randomized clinical trial in children with cystic fibrosis showed that a behavioral intervention combined with individualized nutritional counseling was superior to control treatment in improving diet, energy intake, and height *z*-score over 18 months,[40] but mental health and quality-of-life outcomes were not assessed. There is a need to conduct clinical trials to assess the efficacy of interventions aimed to improve the psychosocial consequences of impaired growth, with objectives and outcomes ideally developed in partnership with children with CKD and their parents.

Impaired growth in children with CKD may be associated with diminished physical, psychological, and social well-being. Patients experience nutritional challenges with their child's diet and experience decisional uncertainty regarding treatment for growth. Facilitating access to targeted nutritional support and strategies to enhance support informed decision making about treatments may lead to improved growth in children with CKD. This may help to improve their mental health, daily function, satisfaction with treatment, and ultimately their overall health outcomes.

Supplementary Material

Supplementary File (PDF)

Item S1: List of institutional review boards that provided ethics approval.

Article Information

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References

1. Drube J, Wan M, Bonthuis M, et al. Clinical practice recommendations for growth hormone treatment in children with chronic kidney disease. *Nat Rev Nephrol*. 2019;15(9):577-589. doi:10.1038/s41581-019-0161-4
2. Bacchetta J, Harambat J, Cochat P, Salusky IB, Wesseling-Perry K. The consequences of chronic kidney disease on bone metabolism and growth in children. *Nephrol Dial Transplant*. 2012;27(8):3063-3071. doi:10.1093/ndt/gfs299
3. Stonebrook E, Mahan JD. Treatment of growth retardation in a child with CKD. *Clin J Am Soc Nephrol*. 2019;14(11):1658-1660. doi:10.2215/CJN.03960319
4. Al-Uzri A, Matheson M, Gipson DS, et al. The impact of short stature on health-related quality of life in children with chronic kidney disease. *J Pediatr*. 2013;163(3):736-741.e1. doi:10.1016/j.jpeds.2013.03.016
5. Rodig NM, McDermott KC, Schneider MF, et al. Growth in children with chronic kidney disease: a report from the Chronic Kidney Disease in Children Study. *Pediatr Nephrol*. 2014;29(10):1987-1995. doi:10.1007/s00467-014-2812-9
6. Ingulli EG, Mak RH. Growth in children with chronic kidney disease: role of nutrition, growth hormone, dialysis, and steroids. *Curr Opin Pediatr*. 2014;26(2):187-192. doi:10.1097/MOP.0000000000000070
7. Haffner D, Zivicnjak M. Pubertal development in children with chronic kidney disease. *Pediatr Nephrol*. 2017;32(6):949-964. doi:10.1007/s00467-016-3432-3
8. Rees L, Mak RH. Nutrition and growth in children with chronic kidney disease. *Nat Rev Nephrol*. 2011;7(11):615-623. doi:10.1038/nrneph.2011.137
9. Fine RN. Etiology and treatment of growth retardation in children with chronic kidney disease and end-stage renal disease: a historical perspective. *Pediatr Nephrol*. 2010;25(4):725-732. doi:10.1007/s00467-009-1409-1
10. Van Huis M, Bonthuis M, Sahpazova E, et al. Considerable variations in growth hormone policy and prescription in paediatric end-stage renal disease across European countries—a report from the ESPN/ERA-EDTA registry. *Nephrol Dial Transplant*. 2016;31(4):609-619. doi:10.1093/ndt/gfv105
11. Akchurin OM, Kogon AJ, Kumar J, et al. Approach to growth hormone therapy in children with chronic kidney disease varies across North America: the Midwest Pediatric Nephrology Consortium report. *BMC Nephrol*. 2017;18(1):181. doi:10.1186/s12882-017-0599-1
12. Rees L. Growth hormone therapy in children with CKD after more than two decades of practice. *Pediatr Nephrol*. 2016;31(9):1421-1435. doi:10.1007/s00467-015-3179-2
13. Tong A, Samuel S, Zappitelli M, et al. Standardised Outcomes in Nephrology—Children and Adolescents (SONG-Kids): a protocol for establishing a core outcome set for children with chronic kidney disease. *Trials*. 2016;17:401. doi:10.1186/s13063-016-1528-5
14. 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. doi:10.1016/j.kint.2020.05.054
15. Logeman C, Guha C, Howell M, et al. Developing consensus-based outcome domains for trials in children and adolescents with CKD: an international Delphi survey. *Am J Kidney Dis*. 2020;76(4):533-545. doi:10.1053/j.ajkd.2020.03.014
16. Tate JA, Happ MB. Qualitative secondary analysis: a case exemplar. *J Pediatr Health Care*. 2018;32(3):308-312. doi:10.1016/j.pedhc.2017.09.007
17. Ruggiano N, Perry TE. Conducting secondary analysis of qualitative data: should we, can we, and how? *Qual Soc Work*. 2019;18(1):81-97. doi:10.1177/1473325017700701
18. 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. doi:10.1053/j.ajkd.2018.12.040
19. Backeljauw P, Cappa M, Kiess W, et al. Impact of short stature on quality of life: a systematic literature review. *Growth Horm IGF Res*. 2021:57-58. doi:10.1016/j.ghir.2021.101392.101392.
20. Francis A, Didsbury MS, van Zwieten A, et al. Quality of life of children and adolescents with chronic kidney disease: a cross-sectional study. *Arch Dis Child*. 2019;104(2):134-140. doi:10.1136/archdischild-2018-314934
21. 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. doi:10.1542/peds.2009-0085
22. Kang NR, Ahn YH, Park E, et al. Mental health and psychosocial adjustment in pediatric chronic kidney disease derived from the KNOW-Ped CKD study. *Pediatr Nephrol*. 2019;34(10):1753-1764. doi:10.1007/s00467-019-04292-w
23. Broyer M, Le Bihan C, Charbit M, et al. Long-term social outcome of children after kidney transplantation. *Transplantation*. 2004;77(7):1033-1037. doi:10.1097/01.tp.0000120947.75697.8b
24. Tjaden LA, Maurice-Stam H, Grootenhuis MA, Jager KJ, Groothoff JW. Impact of renal replacement therapy in childhood on long-term socioprofessional outcomes: a 30-year follow-up study. *J Pediatr*. 2016;171:189-195.e1-2. doi:10.1016/j.jpeds.2015.12.017
25. Reynolds JM, Wood AJ, Eminson DM, Postlethwaite RJ. Short stature and chronic renal failure: what concerns children and parents? *Arch Dis Child*. Jul 1995;73(1):36-42. doi:10.1136/adc.73.1.36
26. Jamieson N, Fitzgerald D, Singh-Grewal D, Hanson CS, Craig JC, Tong A. Children's experiences of cystic fibrosis: a systematic review of qualitative studies. *Pediatrics*. 2014;133(6):e1683-e1697. doi:10.1542/peds.2014-0009

27. Lorne H, Newman CJ, Unger S. Is height important for quality of life in children with skeletal dysplasias? *Eur J Med Genet*. 2020;63(4):103816. doi:10.1016/j.ejmg.2019.103816
28. Nicholas DB, Otley A, Smith C, Avolio J, Munk M, Griffiths AM. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health Qual Life Outcomes*. 2007;5:28. doi:10.1186/1477-7525-5-28
29. Savage E, Callery P. Weight and energy: parents' and children's perspectives on managing cystic fibrosis diet. *Arch Dis Child*. 2005;90(3):249-252. doi:10.1136/adc.2004.056804
30. Greenbaum LA, Hidalgo G, Chand D, et al. Obstacles to the prescribing of growth hormone in children with chronic kidney disease. *Pediatr Nephrol*. 2008;23(9):1531-1535. doi:10.1007/s00467-008-0857-3
31. Aier A, Pais P, Raman V. Psychological aspects in children and parents of children with chronic kidney disease and their families. *Clin Exp Pediatr*. 2022;65(5):222-229. doi:10.3345/cep.2021.01004
32. Cupisti A, Gallieni M, Avesani CM, D'Alessandro C, Carrero JJ, Piccoli GB. Medical nutritional therapy for patients with chronic kidney disease not on dialysis: the low protein diet as a medication. *J Clin Med*. 2020;9(11):3644. doi:10.3390/jcm9113644
33. Hoshino J. Renal rehabilitation: exercise intervention and nutritional support in dialysis patients. *Nutrients*. 2021;13(5):1444. doi:10.3390/nu13051444
34. Mason EC, Gaston JE, Pestell CF, Page AC. A comprehensive group-based cognitive behavioural treatment for blood-injection-injury phobia. *Br J Clin Psychol*. 2022;61(2):494-509. doi:10.1111/bjc.12345
35. Kruger DF, LaRue S, Estepa P. Recognition of and steps to mitigate anxiety and fear of pain in injectable diabetes treatment. *Diabetes Metab Syndr Obes*. 2015;8:49-56. doi:10.2147/DMSO.S71923
36. Kalra S, Aggarwal S, Kumar A. Counseling for growth hormone therapy. *Turk Arch Pediatr*. 2021;56(5):411-414. doi:10.5152/TurkArchPediatr.2021.0126
37. Hui WF, Betoko A, Savant JD, et al. Assessment of dietary intake of children with chronic kidney disease. *Pediatr Nephrol*. 2017;32(3):485-494. doi:10.1007/s00467-016-3491-5
38. Mouslih A, El Rhazi K, Bahra N, Lakhdar Idrissi M, Hida M. Gluten-free diet compliance in children with celiac disease and its effect on clinical symptoms: a retrospective cohort study. *Cureus*. 2023;15(12):e50217. doi:10.7759/cureus.50217
39. Cadario F, Prodam F, Pasqualicchio S, et al. Lipid profile and nutritional intake in children and adolescents with type 1 diabetes improve after a structured dietician training to a Mediterranean-style diet. *J Endocrinol Invest*. 2012;35(2):160-168. doi:10.3275/7755
40. Powers SW, Stark LJ, Chamberlin LA, et al. Behavioral and nutritional treatment for preschool-aged children with cystic fibrosis: a randomized clinical trial. *JAMA Pediatr*. 2015;169(5):e150636. doi:10.1001/jamapediatrics.2015.0636

Patient, Parental, and Health Professional Perspectives on Growth in Children With CKD

Setting & Participants

Secondary analysis of all qualitative studies from SONG-Kids initiative

- **120 patients with CKD aged 8-21 years**
- **250 caregivers**
- **445 health professionals**

- **16 focus groups**
- **1 online Delphi study**
- **2 consensus workshops**

53 countries

Themes

Diminished psychological wellbeing
Compared to and judged by peers, tired of explaining to others, damaging self-esteem

Constrained life participation and enjoyment
Deprived of normal school experiences, excluded from sports or competed at an unfair disadvantage, impaired quality of life in adulthood

Grappling with impacts of symptoms and treatment
Difficulty understanding short stature and seeking help, concerns regarding lack of appetite, bone pains, medication side effects, and growth hormone treatment

Facilitating timely intervention and optimizing outcomes
Short stature as early indicator of kidney disease, track growth progress and assess management of disease, maximize transplant outcomes, minimize morbidity

Keeping growth and health priorities in perspective
Prioritize quality of life and survival, achieved adequate height

CONCLUSION: Growth-specific psychosocial support and enabling informed decision-making on treatments may improve growth and overall health outcomes in pediatric CKD.

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