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Patient and caregiver perspectives on blood pressure in children with chronic kidney disease

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Patient and caregiver perspectives on blood pressure in children with chronic kidney disease

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Running head: Blood pressure in children with CKD

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ABSTRACT

Background. Over 50% of children with chronic kidney disease (CKD) have uncontrolled hypertension, increasing their long-term risk of cardiovascular disease and progression to kidney failure. Children receiving medications or dialysis may also experience acute blood pressure fluctuations accompanied by debilitating symptoms. We aimed to describe the perspectives of children with CKD and their parental caregivers on blood pressure, to inform patient-centered care.

Methods. Secondary thematic analysis was conducted on qualitative data from the Standardized Outcomes in Nephrology – Children and Adolescents initiative, encompassing 16 focus groups, an international Delphi survey, and two consensus workshops. We analyzed responses from children with CKD (aged 8-21 years) and caregivers (of children aged 0-21 years) pertaining to blood pressure.

Results. Overall, 120 patients and 250 caregivers from 22 countries participated. We identified five themes: invisibility and normalization (reassured by apparent normotension, absence of symptoms, expected links with CKD); confused by ambiguity (hypertension indistinguishable from cardiovascular disease, questioning need for prophylactic intervention, frustrated by inconsistent messages, struggling with technical skills in measurement); enabling monitoring and maintaining health (gauging wellbeing, preventing vascular complications); debilitating and constraining daily living (provoking anxiety and agitation, helpless and powerless, limiting life activities); and burden of medications (overwhelmed by quantity of tablets, distress from unexpected side effects).

Conclusions. For children with CKD and their caregivers, blood pressure was an important health indicator, but uncertainty around its implications and treatment hampered management. Providing educational resources to track blood pressure, and minimizing symptoms and treatment burden, may improve outcomes in children with CKD.

Keywords: blood pressure, chronic kidney disease, children, kidney replacement therapy, patient-centered care

KEY LEARNING POINTS

What is already known about this subject?

- The management of blood pressure in children with CKD is often complicated by uncertainty and anxiety around monitoring and treatment side effects.
- A patient-centered approach to blood pressure management is required, since children have unique concerns which they may not express in clinical settings, and their caregivers often assume the responsibilities of healthcare interpreters and technicians to monitor their child's blood pressure and assist with prescribed therapies.
- However, there are scarce data on the perspectives of children with CKD and their caregivers regarding blood pressure.

What this study adds?

- Parents of children with CKD who had well-controlled blood pressure were sometimes unaware that it was a problem, and in the absence of symptoms, some questioned the need for anti-hypertensive medications.
- Children and their parents regarded blood pressure monitoring as a simple strategy to preserve kidney function and mitigate the risk of vascular complications, although for others, hypertension was indiscernible from cardiovascular disease.
- Blood pressure was used to gauge fluid status in children receiving dialysis, and prolong graft survival in transplant recipients, but patients and parents were often distressed by the substantial pill burden required for blood pressure control, and felt powerless from life-threatening hypertensive episodes.

What impact this may have on practice or policy?

- Consistent and comprehensive education about blood pressure control, including measurement and tracking techniques, should be provided for parents and adolescent children to encourage self-management, address assumptions, and resolve ambiguities around blood pressure targets and terminology.
- Shared decision-making about blood pressure management should address the burden of polypharmacy, symptoms and side effects, and impact on life activities, to promote a better understanding of treatment goals.
- Children and caregivers should be offered psychosocial support where available, to address possible unresolved or underlying anxiety from life-threatening blood pressure complications.

INTRODUCTION

Approximately 54-70% of children with chronic kidney disease (CKD) have inadequately or uncontrolled hypertension [1-4], which is a major risk factor for cardiovascular mortality and morbidity, cerebrovascular disease, visual deficits, and neurocognitive delay [2, 5]. Hypertension is associated with the progression of CKD towards kidney failure requiring kidney replacement therapy [2, 6]. Intradialytic hypotension or acute hypertensive episodes may cause debilitating symptoms and anxiety in children receiving dialysis [7-9]. Moreover, in children with a kidney transplant, hypertension increases the risk of graft loss [10].

The management of blood pressure in children with CKD is often complicated by uncertainty and anxiety around monitoring and treatment side effects. While anti-hypertensive therapy is reno-protective in children with Stages 2-4 CKD [11], there is limited data on the real-world efficacy of treatment plans or whether they improve patient-related outcome measures [6, 10, 12]. Anti-hypertensive medications in children can also cause hypotension, hyperkalemia or even worsening of kidney function [13]. Studies have found that adult patients with CKD felt incapacitated by intradialytic hypotensive episodes, that their concerns about blood pressure were dismissed, and overwhelmed by polypharmacy and the responsibilities of self-management [14, 15]. However, there are scarce data on the perspectives of children with CKD and their caregivers regarding blood pressure.

The complexities in monitoring and treating blood pressure in children with CKD highlight the need for patient-centered management [12]. Parents of children with CKD often assume the role of healthcare interpreters, advisers, and technicians to monitor their child's blood pressure and assist with prescribed therapies [16]. Children with CKD also have unique priorities that they may not express in clinical settings [17]. The aim of this study was to describe the perspectives of children with CKD and their caregivers on all aspects of blood pressure, to inform strategies that address their concerns, preferences, and needs.

MATERIALS AND METHODS

Context and sources of data

We conducted a secondary analysis of qualitative data from the Standardized Outcomes in Nephrology – Children and Adolescents (SONG-Kids) initiative [18], which was established to generate consensus-based core outcomes to be reported in all trials in children with all stages of CKD [18]. The SONG-Kids core outcomes are life participation, survival, kidney function and infection [19]. Blood pressure is a second-tier outcome, i.e. critically important to some stakeholder groups, to be reported in some trials in children with CKD [19].

Secondary analysis of qualitative data uses existing data collected for another purpose to address a different or related question that had not been analyzed in the primary studies [20, 21]. We conducted a secondary analysis of all qualitative data from the SONG-Kids studies comprising 16 focus groups [22], free text comments from an international Delphi survey [23], and two consensus workshops [19]. We extracted and analyzed the responses of child and adolescent patients (aged 8-21 years) and caregivers (of children aged 0-21 years) directly related to blood pressure. The Delphi survey and consensus workshops included specific discussion questions pertaining to blood pressure (Supplementary File 1). Overall, 120 patients and 250 parents or family members from 22 countries participated. The institutions that provided ethics approval are listed in Supplementary File 2.

Data extraction and analysis

Participant quotations were extracted from the original transcripts of the SONG-Kids focus groups, free text comments from the Delphi survey, and the consensus workshops. JW performed preliminary coding to identify initial themes and subthemes. To enhance the analytical framework and to ensure the themes

1 reflected the full range and depth of data collected, two independent second investigators who had read the
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3 transcripts (AT, SC) reviewed and discussed the themes with JW until consensus was reached [24]. The
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5 transcripts were then reviewed line-by-line and coded using HyperRESEARCH version 4.5.1
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8 (ResearchWare Inc., Randolph, Massachusetts, USA). We compared themes among patients and caregivers,
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10 and by treatment modality.
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RESULTS

Participant characteristics are summarized in Table 1. Overall, 34 patients and 62 caregivers from 14 countries participated in the nominal group technique, 72 patients and 132 caregivers from 15 countries participated in the Delphi survey, and 14 patients and 56 caregivers from 3 countries were involved in the consensus workshops. We identified five themes: invisibility and normalization, confused by ambiguity, enabling monitoring and maintaining health, debilitating and constraining daily living, and burden of medications (Figure 1). These themes were also cross-tabulated by treatment modality (Figure 2). Selected illustrative quotations for each theme are provided in Table 2.

Invisibility and normalization

Reassured by apparent normotension: With well-maintained normotension in the child, some parents felt unaware of or unimpacted by blood pressure. Some were uncertain about the impact of high blood pressure – “what does that have to do with kidney disease?” (parent) because “it wasn’t explained to me that it was a problem.” (patient) Children felt reassured when their blood pressure was well-controlled by medications or even that “blood pressure isn’t affecting us.” (patient) Healthcare professionals and parents sometimes took responsibility for the child’s blood pressure and did “everything that they needed to do” (parent) to minimize the burden on the child and protect their sense of normality.

Absence of symptoms: Some patients and parents felt unaware of blood pressure due to the lack of symptoms. Consequently, parents were alarmed when they discovered their child had high blood pressure because “you’d never be able to tell it, looking at him.” Some parents were concerned that asymptomatic hypertension or end-organ effects (e.g. on the heart) could go undiagnosed: “We had the electrocardiogram done and that’s how we found out [about left ventricular hypertrophy]. He had no symptoms, no swelling.”

1 *Expected links with CKD:* Some parents expected abnormal blood pressure to be a consequence of CKD
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3 “because it comes with the kidney disease, with the fluid.” Some were uncertain about “what came first, the
4 kidney disease or the high blood pressure?” Other parents accepted that anti-hypertensive medication and
5 dialysis were part of routine management – “it’s something that can be treated ... that’s what the dialysis is
6 for.”
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15 Confused by ambiguity

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20 *Hypertension indistinguishable from cardiovascular disease:* Parents and patients perceived that blood
21 pressure and cardiovascular disease were “intimately related” (parent) and for some, even “the same thing.”
22 (patient) Others saw blood pressure as a “symptom of your heart” (patient) and some parents thought that
23 children may “be worried about [blood pressure] because they [were] worried about the cardiovascular
24 disease.”
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33 *Questioning need for prophylactic intervention:* Some parents and children wondered about the need for
34 anti-hypertensive medications, particularly when the child had never recorded abnormal blood pressure
35 values or experienced related adverse events. One parent was unsure that the medication could be a
36 “preventative to protect his kidney from overworking.” Another parent also explained: “After my son’s
37 transplant he did ask, ‘why am I on blood pressure medication, my blood pressure has always been good?’”
38 (parent)
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49 *Frustrated by inconsistent messages:* Parents felt frustrated when they perceived that clinicians provided
50 conflicting or confusing messages regarding their child’s blood pressure. Some were exasperated by the
51 “different levels of importance” placed on blood pressure by different clinicians. They felt forced to “make a
52 decision about an acceptable blood pressure level” for their child, so that they would not be worried
53 constantly. Another parent felt dismissed and “rather annoyed at the assumption” of a clinician who
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1 attributed high blood pressure readings to white coat hypertension, as her child had not “had his blood
2 pressure taken anywhere other than at the hospital.”
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8 *Struggling with technical skills in measurement:* Some parents struggled with the technical skills involved in
9 measuring blood pressure – “We were going back to the hospital because ... no one told me how to work the
10 blood pressure cuff.”
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17 Enabling monitoring and maintaining health

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22 *Gauging wellbeing:* Parents recognized that blood pressure measurement was part of “standard testing done
23 at every appointment,” and believed that managing blood pressure was critical to preserve “the heart, the
24 kidney function, and the general wellbeing of the child.” The “silent” nature of CKD meant that parents
25 relied on blood pressure as a tangible indicator for their child’s health, and appreciated the accessibility of
26 blood pressure monitoring as compared to other diagnostic investigations (e.g. echocardiograms). Parents of
27 patients receiving dialysis felt they had to be more vigilant with monitoring blood pressure because it was a
28 means of gauging whether their child was fluid overloaded or had “too much salt.” Some parents were wary
29 of the risks of blood pressure on kidney function or graft survival and “the need to preserve what kidney
30 function [they’ve] got.”
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45 *Preventing vascular complications:* Blood pressure control was viewed to mitigate “risks to the heart and
46 vascular system,” prevent “eye problems” and reduce “fluid around the heart.” Some parents were worried
47 that an accurate evaluation of their child’s cardiovascular health was “tricky,” but their concerns were
48 allayed with “constantly monitoring” their child’s blood pressure. Other parents were anxious that high
49 blood pressure was a strong predictor for cardiovascular disease, particularly those whose child had
50 experienced an acute complication (e.g. heart failure), or if they themselves had hypertension.
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Debilitating and constraining daily living

Provoking anxiety and agitation: Some children and their caregivers reported that blood pressure fluctuations could lead to anxiety attacks or disabling dizziness in different settings. During hypertensive episodes, patients reported “panic attacks,” their “heart beating really fast,” and feeling “woozy” with their arms turning red. Parents were also worried about their child’s “racing heart and nervousness,” headaches, or the sensation of being “in a fog.” Some parents were concerned that their child may have a hypotensive episode and “pass out in class.”

Helpless and powerless: Life-threatening hypertensive episodes instigated powerlessness, vulnerability and insecurity in patients and parents. Patients recounted distressing incidents, in which they thought they may not survive – “I get concerned with blood pressure because I almost died.” Parents were frightened by their child’s severe hypertensive episodes, having to confront the severity of their illness and the possibility their child could be “going to die.” (parent) Some parents felt helpless when medications or dialysis did not relieve their child’s “ridiculously high blood pressure” or associated symptoms such as headaches.

Limiting life activities: Children felt that blood pressure problems limited their lifestyle and future goals. One child was disappointed that he was not allowed to sleep over at a friend’s house because of his mother’s concerns that he may forget to take his blood pressure medication. Another patient realized that his future career opportunities were contingent on whether “the job [was] too physical” or “stressful for [him], because it could get [his] blood pressure high, and [he] could pass out.” Parents were also concerned that symptomatic fluctuations in blood pressure could disrupt their child’s education or reduce the time spent “hanging out with friends.”

Burden of medications

Overwhelmed by quantity of tablets: Some parents felt overwhelmed by the large dosages and number of anti-hypertensive medications prescribed for their children – “My daughter is taking adult doses of blood pressure medication and is only 7 years old.” Some were frustrated by the “constant changes to medication type and dosages,” and one parent reported that their child had to take “seven different blood pressure medications.”

Distress from unexpected side effects: The side effects of anti-hypertensives, and unexpected consequences of other medications on blood pressure were distressing for patients and their parents, particularly if they felt inadequately warned about them. Parents reported that blood pressure medications caused their child to experience “heart palpitations” and feel “tired,” “cranky” or “dizzy.” One parent was upset about the impact of corticosteroids on blood pressure because “she was already almost in stroke area ... we just had to ride out the prednisone.”

DISCUSSION

Parents of children with CKD who had well-controlled blood pressure were sometimes unaware that it was a problem or accepted anti-hypertensive medications as a routine component of managing CKD. In the absence of symptoms, some children and their parents questioned the need for anti-hypertensive medications. Children and their parents regarded blood pressure monitoring as a simple strategy to preserve kidney function and prevent vascular complications, although for others, hypertension was indiscernible from cardiovascular disease. Life-threatening hypertensive episodes instigated anxiety and powerlessness in children with CKD and their parents, and impinged upon their daily activities. In children receiving dialysis, blood pressure was used to gauge fluid status, and in kidney transplant recipients it was managed to prolong graft survival. Parents were frustrated by inconsistent or insufficient advice from clinicians regarding blood pressure and its measurement, while some were distressed by the substantial pill burden required for blood pressure control and felt they lacked awareness about hypertension-inducing medications.

There were some differences in the perspectives on blood pressure between children and caregivers, and by treatment modality. Caregivers were concerned about the potential harms of taking large doses of antihypertensive medications, side effects, and being technically competent in monitoring their child's blood pressure. They relied on knowing their child's blood pressure to gauge their kidney and overall health. These concerns may reflect their perceived responsibility for managing their child's health and treatment regimen, and protecting their child's sense of normality by censoring information about blood pressure problems. Children with CKD were concerned with the social constraints and debilitating impacts of having blood pressure problems, and older adolescents avoided activities that could elevate their blood pressure. Patients not requiring kidney replacement therapy and their caregivers were concerned about preventing cardiovascular complications and progression of CKD. In addition, hypotensive episodes were particularly frightening and debilitating for children requiring dialysis and their caregivers.

1 The lack of awareness about blood pressure, including its associated risk with disease progression, has also
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3 been found in adults with CKD, particularly in those who are asymptomatic [25, 26]. This was similar to our
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5 findings where parents and children found it difficult to recognize blood pressure problems and risks
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7 because they were often asymptomatic with no discernible signs. Adult patients receiving dialysis have
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9 reported debilitating hypotensive symptoms and fear of “crashes” [14]. Children with CKD have described
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11 heart palpitations, anxiety, and feelings of exhaustion before, during and after hemodialysis [27], although
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13 these concerns have not been attributed directly to blood pressure. Some adult patients with CKD were not
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15 aware nor concerned about their risks cardiovascular mortality [25]. In our study, caregivers of children with
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17 CKD were acutely aware and concerned about the cardiovascular complications associated with blood
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19 pressure, likely due to their parental roles and responsibility for their child’s health. In adults with CKD who
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21 had experienced major adverse events requiring hospitalization, some were resigned to the possibility of
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23 early death and were less motivated to monitor their blood pressure [25]. In contrast, we identified
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25 unresolved and underlying anxiety in children with CKD and caregivers who had encountered life-
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27 threatening blood pressure problems, and these events may have deeply ingrained in them the importance of
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29 blood pressure control.
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38 We synthesized data from three large and methodologically diverse datasets that involved 370 children with
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40 CKD and their caregivers across 22 countries, and generated a wide range of novel and rich insights on their
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42 perspectives about blood pressure. However, we acknowledge some potential limitations in this study. Most
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44 participants were from English-speaking high-income countries [19, 22, 23, 28]. Since this was a secondary
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46 analysis, detailed probes to elicit detailed perspectives on blood pressure may not have been used in all
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48 original studies as the primary aim was not focused on blood pressure.
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54 The challenges and concerns regarding blood pressure management as identified by children with CKD and
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56 their caregivers signal there is an ongoing need to improve education, self-management and shared decision-
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58 making in clinical practice (Table 3). Consistent and comprehensive education about blood pressure control
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1 could address assumptions surrounding apparent normotension particularly in asymptomatic patients, and
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3 resolve ambiguities around blood pressure targets and terminology [29, 30]. Guidance on how to measure
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5 blood pressure should be provided for parents and adolescent children, and self-management strategies such
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7 as keeping a blood pressure log-book should be encouraged [14, 31]. Shared decision-making about blood
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9 pressure management may entail explicit discussion about the burden of polypharmacy, including symptoms
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11 and side effects, and impact on life activities and ambitions in the context of adhering to blood pressure
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13 targets, to promote a better understanding of the goals of therapy and its proportionate risks [31, 32].
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15 Specific counselling may be required to address possible unresolved trauma and anxiety, particularly for
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17 children with CKD who have experienced life-threatening hypertensive events. Counselling should also
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19 attend to parents at risk of being overwhelmed by caregiver responsibilities [33]. These strategies may be
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21 used to complement currently available information for caregivers and clinical practice guidelines for
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23 physicians [34-36].
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31 Further studies may examine interventions to support children with CKD and their caregivers in monitoring
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33 and managing blood pressure. These could harness digital health technology, for example mobile apps and
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35 electronic reminders to take medications [31, 37]. A trial in adults with CKD using a smartphone-based self-
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37 management system and Bluetooth-enabled home blood pressure monitoring device found a mean reduction
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39 in systolic blood pressure of 3.4 mmHg in the intervention arm [38]. Another trial in adults showed that
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41 home blood pressure monitoring, accompanied by a mobile app that tracked blood pressure readings and
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43 delivered daily medication reminders, increased empowerment and motivation, improved treatment
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45 adherence, and informed clinical decisions regarding medication [39]. Furthermore, although some countries
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47 lack the resources required for routine ambulatory blood pressure monitoring (ABPM), it is increasingly
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49 recognized as advantageous in detecting masked hypertension and evaluating the efficacy of blood pressure
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51 management in children with CKD [10, 36, 40]. A recently-developed wrist wearable for ABPM may have
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53 potential [41], although its acceptability and effectiveness would need to be evaluated in children of
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55 different ages with CKD.
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3 Children with CKD and their caregivers valued blood pressure as an important indicator for health, but still
4 had some uncertainty and confusion about its significance and the goals of therapy, and this hampered
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6 management. Patients were frustrated when fluctuating blood pressure levels restricted their choices of daily
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8 activities or career, and were distressed by traumatic life-threatening hypertensive episodes. Providing
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10 education and resources to monitor and interpret blood pressure, and minimizing symptoms and treatment
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12 burden may help to achieve better blood pressure control and outcomes in children with CKD.
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CONFLICT OF INTEREST STATEMENT

None declared.

AUTHORS' CONTRIBUTIONS

Research idea and study design: JGW, AT, NE, KEM, CSH, AB, NA, AS, AD, AAE, CG, DSG, DB, HY, JG, MZ, SIA, SLF, SS, SAC, AW, JK, DM, TG, JCC; data acquisition: JGW, AT, NE, KEM, CSH, AB, SS, SAC, AW, JK, TG; data analysis/interpretation: JGW, AT, NE, KEM, CSH, AB, NA, AS, AD, AAE, CG, DSG, DB, HY, JG, MZ, SIA, SLF, SS, SAC, AW, JK, DM, TG, JCC; supervision or mentorship: AT.

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Table 1. Participant characteristics

Characteristic	Nominal Group Technique N=96[22] (%)	Delphi survey N=204[23] (%)	Consensus workshops N=70[19] (%)
Participant group			
Patient	34 (35)	72 (35)	14 (20)
Parent/family member	62 (65)	132 (65)	56 (80)
Gender			
Male	32 (33)	67 (33)	25 (36)
Female	64 (67)	134 (66)	41 (59)
Chronic kidney disease stage (patient)			
CKD*	17 (50)	59 (30)	ns
Dialysis	5 (15)	53 (25)	ns
Transplant	12 (35)	92 (45)	ns
Patients age group (years)			
8 – 18	31 (91)	49 (68)	9 (64)
19 – 21	3 (9)	16 (22)	3 (21)
Country			
Australia	24 (25)	27 (13)	28 (40)
United States	23 (24)	69 (34)	37 (53)
Canada	13 (14)	17 (8)	1 (1)
United Kingdom	ns [†]	22 (11)	ns
Singapore	0 (0)	21 (10)	ns
India	ns [†]	17 (8)	ns
New Zealand	ns [†]	15 (7)	ns
Other [‡]	27 (28)	16 (8)	ns

*CKD, chronic kidney disease not requiring kidney replacement therapy; N of patients, parents or family member; Delphi survey: a sequential, consensus-based survey method; ns: not stated.

[†]India, England and New Zealand are also included in 'Other' for NGT. [‡]Other includes up to 18 countries: England, Ethiopia, Fiji, France, India, Kenya, Malaysia, Mexico, Morocco, Myanmar, Pakistan, Philippines, Portugal, New Zealand, Poland, Saudi Arabia, Somalia and Vietnam. Percentages do not always add up to 100 due to undisclosed responses (excluded).

1 **Table 2. Selected quotations to support each theme**

Theme	Quotations
Invisibility and normalization	
Reassured by apparent normotension	<p data-bbox="526 271 2080 327">"I was shocked when I saw that question... I thought what does [blood pressure] have to do with kidney disease...we haven't advanced to transplant stage or whatever, I don't know when that becomes an issue." (C)</p> <p data-bbox="526 327 2080 383">"For many, many years he was on ACE inhibitors so I said, your doctors have done everything that they needed to do to take care of your blood pressure, and you just never thought about it because you were just a kid, and you did your kid things, which I want him to do." (C)</p> <p data-bbox="526 383 2080 438">"For me growing up it was like [blood pressure] didn't really matter. Not that it didn't matter but we didn't talk about it as much. It wasn't explained to me that it was a problem." (P)</p> <p data-bbox="526 438 2080 494">"I think blood pressure isn't affecting us because we are taking tablets daily for the blood pressure." (P)</p>
Absence of symptoms	<p data-bbox="526 494 2080 526">"His blood pressure went up to 140/90 and that was the week before his first birthday. And you'd never, ever be able to tell it, looking at him." (C)</p> <p data-bbox="526 526 2080 582">"[The doctor] said his blood pressure is too high, and to get an electrocardiogram (EKG) done. We had the EKG done and that's how we found out. He was 13 at the time, 14 now. He had no symptoms, no swelling." (C)</p> <p data-bbox="526 582 2080 630">"some of his friends would go 'Oh, there's nothing wrong with you. You look fine' and I'm just like 'Oh my god', right?" (C)</p>
Expected links with CKD	<p data-bbox="526 630 2080 686">"The thing about blood pressure... I don't look at it as a big thing because it comes with the kidney disease, with the fluid. They're going to have high blood pressure, that's what the dialysis is for." (C)</p> <p data-bbox="526 686 2080 726">Parent 1: "Yes, he takes medication for high blood pressure." Parent 2: "OK, so that's like a common no matter which stage you're on." (C)</p> <p data-bbox="526 726 2080 758">"It's like, what came first, the kidney disease or the high blood pressure?" (C)</p>
Confused by ambiguity	
Hypertension indistinguishable from cardiovascular disease	<p data-bbox="526 798 2080 853">"Aren't [blood pressure and cardiovascular disease] intimately related? That's what I thought when I was doing the survey. That confused me when I actually did the survey." (C)</p> <p data-bbox="526 853 2080 909">"Isn't [blood pressure and cardiovascular disease] the same thing? That's hypertension because hypertension is your heart. So well both. It's more of the cardiovascular because the hypertension is actually just a symptom of your heart." (P)</p> <p data-bbox="526 909 2080 989">"The underlying not-so-obvious cases of cardiovascular disease led us down the path of almost joining them together, so cardiovascular disease [includes] hypertension/blood pressure." (C)</p>
Questioning need for prophylactic intervention	<p data-bbox="526 989 2080 1021">"Well, I don't know if he's got high blood pressure, or if he's on it as a preventative to protect his kidney from overworking." (C)</p> <p data-bbox="526 1021 2080 1053">"It jacks the blood pressure up. And then I didn't realize that if we were on the sodium diet due to the prednisone or due to the kidneys." (C)</p> <p data-bbox="526 1053 2080 1093">"After my son's transplant he did ask mum, 'Why am I on blood pressure medication? My blood pressure has always been good.' " (C)</p>
Frustrated by inconsistent messages	<p data-bbox="526 1093 2080 1181">"Doctors and nurses who cared for my daughter placed different levels of importance on blood pressure levels which resulted in conflicting advice. I sometimes felt that I had to make a decision about an acceptable blood pressure level because there wasn't consensus between the two professions." (C)</p> <p data-bbox="526 1181 2080 1252">"In the latest letter from the specialist the mention of White Coat Hypertension was stated. Rather annoyed at this assumption, as he has not had his blood pressure taken anywhere other than at the hospital." (C)</p>
Struggling with technical skills in measurement	<p data-bbox="526 1252 2080 1316">"I go home, and they're like, "and you're going to have to monitor her blood pressure but don't worry, we're going to get you a cuff' ... We were going by ambulance back to the hospital because I didn't have the blood pressure cuff, no one told me how to work the blood pressure cuff." (C)</p>
Enabling monitoring and maintaining health	

1	Gauging wellbeing	"I think it is important to keep blood pressure in check, so monitoring is important. And that sort of impacts a lot of other things. It impacts the heart, the kidney function, the general wellbeing of the child." (C)
2		"I can see that [blood pressure] would be high on the radar if you were looking at sampling all different outcomes because it is an underlying indicator of too much fluid and other things at risk too much salt." (C)
3		"For us, with kidney disease being the silent disease and having been through everything that we have been through, blood pressure for us is vital. It is right up there number 1." (C)
4		"Blood pressure is a really important indicator and we are always focused on it and on peritoneal dialysis, are they overloaded?" (C)
5	Preventing vascular complications	"Blood pressure control is something which is checked every time they are in hospital & monitored because we know the risks to the heart & vascular system." (C)
6		"Well she had heart failure 3 times, because she had high blood pressure, so um, yeah, it's very important to regulate, that's why I said regulate the blood pressure." (C)
7		"It's like the CVD is probably more a result of longer of term [blood pressure] issues as you tip out of the younger into the adult." (C)
8		"The assessment of cardiovascular disease is tricky and a risk factor is hypertension so we came to the end where they were both very important, recognizing one was both constantly monitored and the other one you could get surprised with so it should have some prominence." (C)
9		"If you control your blood pressure you are less likely to get a heart disease, so the information about blood pressure can help to prevent." (C)
10	Debilitating and constraining daily living	
11	Provoking anxiety and agitation	"I get concerned with blood pressure because I almost died because of high blood pressure." (P)
12		"The blood pressure was just making his heart go a mile a minute, and he thought he was having a heart attack." (C)
13		"Blood pressure for us is vital because she goes very symptomatic with blood pressure issues. So one time she could have a really low blood pressure and pass out in class, or the next time around she could have a really high blood pressure, have the headaches, have the infection rate." (C)
14		"So we left the hospital thinking "Oh my God, she's going to die" 'cause that's kind of what you feel, right?" (C)
15	Helpless and powerless	"Still headaches every day, high blood pressure, ridiculously high blood pressure that couldn't be controlled with the haemo. Haemo was supposed to help reduce her blood pressure. But when she would go on, it would be high, and when she'd come off, it would be much higher." (C)
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17	Limiting life activities	"Every time I talk to my friend, he always tells me, "You wanna have a sleepover at my house?" And I'm like, "I can't". I don't know. I tell my mum and she's like, "First thing, he has to remember the pills." (P)
18		"Yeah. It depends on if the job is too physical, you do too much work. Also could be dependent on whether it's stressful for you, because it could get your blood pressure high, and you could pass out." (P)
19		"He becomes very symptomatic all he needs is a little bit of fluid in his vascular system and a lot of things go wrong and he's missing TAFE and he's missing hanging out with his friends." (C)
20	Burden of medications	
21	Overwhelmed by quantity of tablets	"Like she wanted to throw up. Because she had so many, she used to be on three high blood pressure medications." (C)
22		"And some of these doses that she's on, she's taking close to the same dose as my mum on her blood pressure medication and its, it's a pain in the toosh, she's 7 years old." (C)
23	Distress from unexpected side effects	"[Blood pressure medication] makes her tired and she can get cranky." (C)
24		"Each of these changes [to blood pressure medication] resulted in physical symptoms such as dizziness, heart palpitations etc." (C)

40 C: caregiver, P: patient

Table 3. Suggestions for clinical practice

Strategy	Suggested Actions or Interventions*
Provide comprehensive education and resolve ambiguities	<ul style="list-style-type: none"> • Provide education on blood pressure control in CKD • Address ambiguities regarding the asymptomatic nature of blood pressure in children • Discuss the benefits of blood pressure control on long-term cardiovascular and kidney health
Promote self-management and monitoring	<ul style="list-style-type: none"> • Provide a blood pressure log-book • Advise parents and adolescent children on how to measure blood pressure • Develop or use mobile apps to enable patients to track their blood pressure targets
Encourage discussion and support shared decision-making	<ul style="list-style-type: none"> • Address concerns about medication, especially polypharmacy and side effects. • Discuss the impact of blood pressure treatment on life activities • Review blood pressure progress and goals regularly • Develop and implement blood pressure management decision aids which consider patient concerns and priorities
Address mental health	<ul style="list-style-type: none"> • Facilitate access to psychological services • Address unresolved trauma related to life-threatening blood pressure events • Discuss the burden of caregiver responsibilities on parents' psychological wellbeing

*These suggestions are based on authors' findings, and require further research to assess their effectiveness in improving blood pressure management in children with CKD.

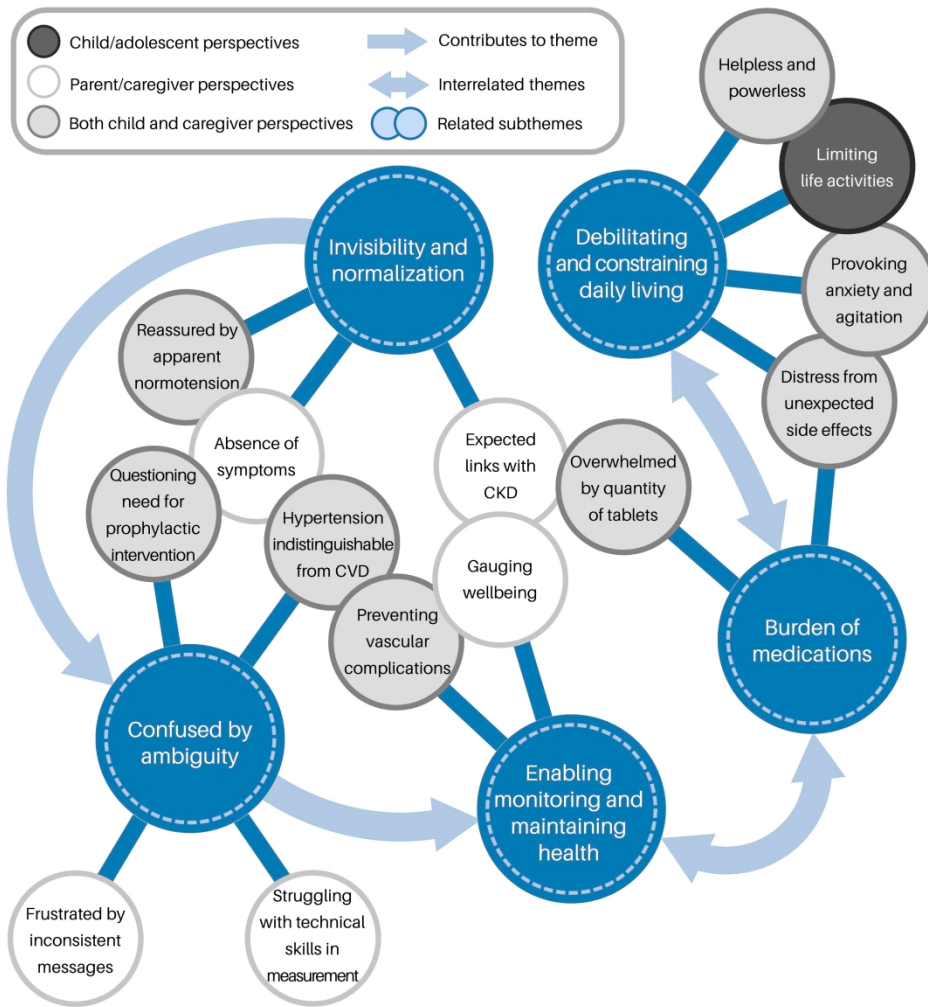
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Figure Legends

Figure 1. Thematic schema

Figure 2. Cross-tabulation of themes by treatment modality and age

For Peer Review

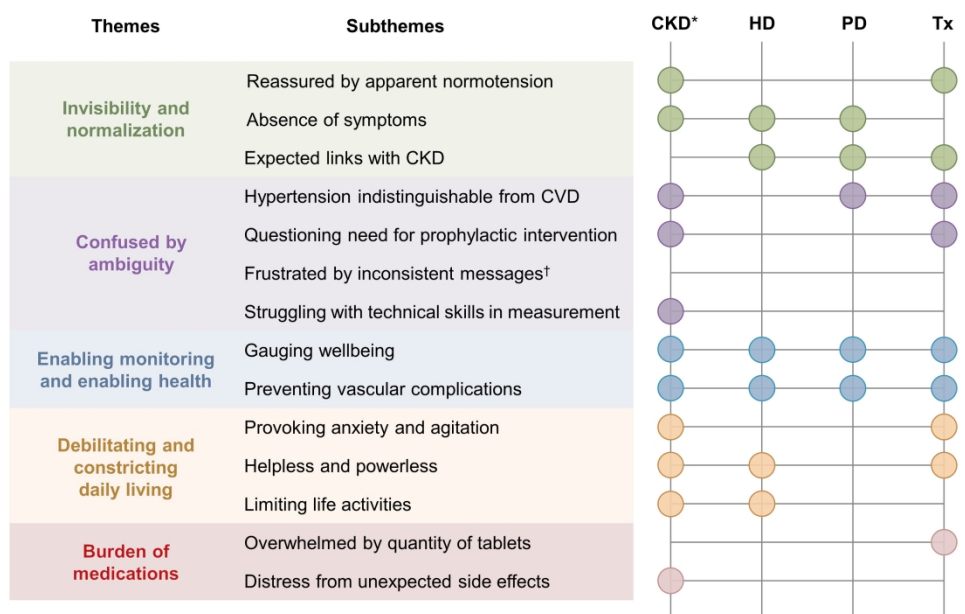


Thematic schema

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*Chronic kidney disease not requiring kidney replacement therapy.
†Data not available. Quotations were tabulated to treatment modality where the information was available in the transcript.

Cross-tabulation of themes by treatment modality and age
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