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Experiences and Needs of Families Caring for Children and Adolescents With Chronic Kidney Disease: A meta-Synthesis



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ABSTRACT

Problem: Families struggle to care for children and adolescents with chronic kidney disease (CKD). They face extensive burden of care and altered family dynamics.

Eligibility criteria: A meta-synthesis review was conducted to explore the experiences and needs of families caring for children and adolescents with CKD using seven electronic databases (CINAHL, EMBASE, ProQuest Dissertations and Theses, PsycINFO, PubMed, Scopus, and Web of Science). The inclusion criteria are (1) qualitative English studies from January 2010 to December 2020 that (2) report personal experiences or needs of (3) family members caring for children and adolescents aged 19 years and below who have been diagnosed with CKD of any stage (4) across all settings. Quality appraisal was done using the Critical Appraisal Skill Program checklist. Data was synthesised using Sandelowski & Barroso's (2007) method.

Sample: 2,236 records were identified and 13 eligible studies were included. Family members involved mothers ($n = 190$), fathers ($n = 83$), siblings ($n = 5$), and grandparents ($n = 2$).

Results: Three themes emerged: (1) demands of caregiving, (2) support systems, and (3) defining and making sense of new reality.

Conclusions: Family caregivers experience overwhelming demands of caregiving and unmet support needs to cope. Appropriate interventions are needed to alleviate their burden.

Implications: Knowledge of learning and support needs of families caring for children with CKD may shape nursing education and practice to cultivate more effective communication for better psychosocial family support.

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Introduction

Background

Chronic kidney disease (CKD) is the presence of structural kidney damage or decreased kidney function for three or more months, with health implications (*Chapter 1: Definition and classification of CKD*, 2013). The worldwide prevalence of pediatric CKD and the incidence of renal replacement therapies in children and adolescents below the age of 20 have been increasing over the years (Baum, 2010; United States Renal Data System, 2020; Wong et al., 2012). CKD in children and adolescents is predominantly due to congenital, acquired, non-glomerular, glomerular and hereditary conditions (Becherucci et al., 2016). The growth and development of children and adolescents with CKD are hindered by disease complications with inevitable lifelong increases in morbidity and mortality (Kaspar et al., 2016).

Pediatric CKD does not solely affect patients' lives. The medical decision-making and responsibility of care of these minors are predominantly managed by their adult family caregivers (Kula & Somers, 2021). Family members divert attention and resources to medical care for young patients with CKD in addition to fulfilling existing familial and social roles. CKD severity dictates involvement in complex pre-dialysis, dialysis, or kidney transplant management, including technical procedures, enforcing medication adherence, and intake restrictions (Tong et al., 2010). Compared to children with other chronic diseases, the financial burden of children with CKD was reportedly greater as they were hospitalized 12 times more often and incurred higher medical costs (Modi et al., 2021). Psychological distress and fatigue from long-term caregiving have reduced the quality of life of parents and may contribute to caregiver burnout (Golics et al., 2013; Wiedebusch et al., 2010). Siblings experience neglect as parents provide more attention to the sick child (Geense et al., 2017). They are at greater risk for developing anxiety, depression, and poorer cognitive development (Dinleyici & Dağlı, 2019; Vermaes et al., 2012).

The physical, psychosocial, and financial experiences of caring for pediatric CKD patients can be overwhelming for families. The Family Adjustment and Adaptation Response (FAAR) Model, a theoretical

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framework on family systems will be adopted to generate insights into families' needs from the chronic stress of handling pediatric CKD while exploring the capabilities and family meanings that aid in adaptation (Patterson, 1988; Patterson & Garwick, 1994).

Existing reviews and gaps

A preliminary search for existing similar reviews was conducted without year limit to prevent duplication (Chalmers et al., 2014). The impact and needs of caring for children and adolescents with CKD were described by six reviews that collectively expressed varying levels of distress, financial strains, disruptions to family relationships, and restricted social life experienced by family caregivers. Three reviewed the experiences of parents (Aldridge, 2008; Ong et al., 2021; Tong et al., 2008), and one only reviewed mothers' needs (Pourghaznein et al., 2018). These reviews lacked valuable input from other family members, such as siblings and grandparents, who are also impacted by pediatric CKD caregiving. The remaining two reviews involved a wide scope of family members but were either limited by treatment modality or lacked trustworthiness. Lomba et al.'s (2014) literature review only studied the impact of peritoneal dialysis while Lise et al. (2016)'s integrative review applied thematic analysis, a qualitative research method (Nowell et al., 2017), on both qualitative and quantitative studies. Reviews by Aldridge (2008) and Tong et al. (2008) were conducted more than 10 years ago and could contain outdated information on parents' experiences.

Significance of review

To the best of the authors' knowledge, no recent qualitative systematic reviews explored the experiences and needs of various family members caring for children and adolescents with CKD across all stages. Since collaboration with caregivers is vital in pediatric CKD management, nurses need to understand the experiences and needs of families to develop relevant resources for pediatric nephrology nursing education and steer clinical research for targeted family support interventions to deliver quality patient and family centered care in clinical practice.

Aims

This systematic review aims to synthesize qualitative evidence in relation to the experiences and needs of families caring for children and adolescents with CKD stages 1 to 5 across all settings.

Review question

What are the (1) experiences and (2) needs of family members caring for children and adolescents with CKD?

Methods

This meta-synthesis review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines found in Appendix A (Moher et al., 2009).

Eligibility criteria

The target population involved family members of children and adolescents who have been diagnosed with CKD (Stage 1 to 5) and are aged 19 years and below (World Health Organization, 2020). Included studies must explore the experiences and needs of family members. A global approach was taken and encompassed all settings. Only qualitative English studies with full text that were published within the past 10 years (January 2010 to December 2020) were included for greater relevance and applicability to current healthcare practices. The detailed inclusion and exclusion criteria are found in Appendix B.

Information sources and search strategy

A pre-planned search using a three-step approach was used to identify relevant published English studies from January 2010 to December 2020. An initial limited search was done on Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed using five concepts (Appendix C). Appropriate keywords, Boolean operators and truncation symbols formed a detailed search strategy. Secondly, the search strategy was implemented across seven electronic databases up to 5 December 2020, tailored with specific syntax and subject headings according to database requirements for comprehensive search results (Appendix C) (Bramer et al., 2018). The databases included CINAHL, Excerpta Medica Database (EMBASE), PsycINFO, PubMed, Scopus and Web of Science. Grey literature was sourced from ProQuest Dissertations and Theses Global to reduce publication bias (Paez, 2017). Lastly, reference lists of eligible studies, Journal of the American Society of Nephrology and Kidney International were hand searched for suitable studies. Authors of studies with insufficient details were contacted for additional information where necessary.

Study selection

All identified citations from database searches were imported into the reference management software EndNote X9. Studies were screened based on title and abstract. Remaining studies were assessed in full text based on eligibility criteria. The entire process was conducted by two independent reviewers to reduce bias (Stoll et al., 2019). Disagreements were resolved after discussions with third reviewer.

Quality appraisal

Quality was assessed by two independent reviewers using the 10-item Critical Appraisal Skills Program (CASP) checklist (Critical Appraisal Skills Program, 2018), the most common tool for appraising qualitative healthcare research (Long et al., 2020). Each item was given a rating of "Yes", "Can't tell" or "No", weighted with scores of "3", "2" and "1" respectively to measure the estimated value of evidence with greater accuracy (Boeije et al., 2011). Inter-rater agreement was determined by the percentage of identical ratings by reviewers. Disagreements were resolved after a discussion between reviewers. Quality appraisal served to enhance the rigor of the synthesis and allow readers to make an evaluation of the quality of the systematic review results (Toye et al., 2014; Walsh & Downe, 2005). Hence, no eligible studies were excluded based on quality criteria.

Data extraction

A standardized data extraction form was used to extract study characteristics via stepwise replication technique by two independent reviewers for dependability (Guba, 1981; Krefting, 1991). Disagreements were resolved upon reaching a consensus after discussions. Relevant first order constructs (participants' quotes in verbatim and non-verbal expressions) and second order constructs (authors' descriptions and interpretations) from the results of eligible studies were also extracted for data analysis and synthesis.

Data synthesis

Two-stage qualitative synthesis was guided by Sandelowski and Barroso (2007). Firstly, a meta-summary involved extracting and grouping findings into statements using thematic analysis (Braun & Clarke, 2012). Quotes on experiences and needs of family members were coded line-by-line and categorized. New categories were created when data did not match pre-existing categories. Themes and subthemes were inductively derived. Data sources were triangulated by constantly comparing meta-summary

findings with individual studies' findings. Effect sizes for themes were calculated by dividing number of studies within each theme by total number of eligible studies for enhanced credibility (Ludvigsen et al., 2016; Sandelowski & Barroso, 2007). The second

step involved meta-synthesis, an interpretive integration that demonstrates relationships between themes to generate newer or deeper meanings behind the experiences and needs of families.

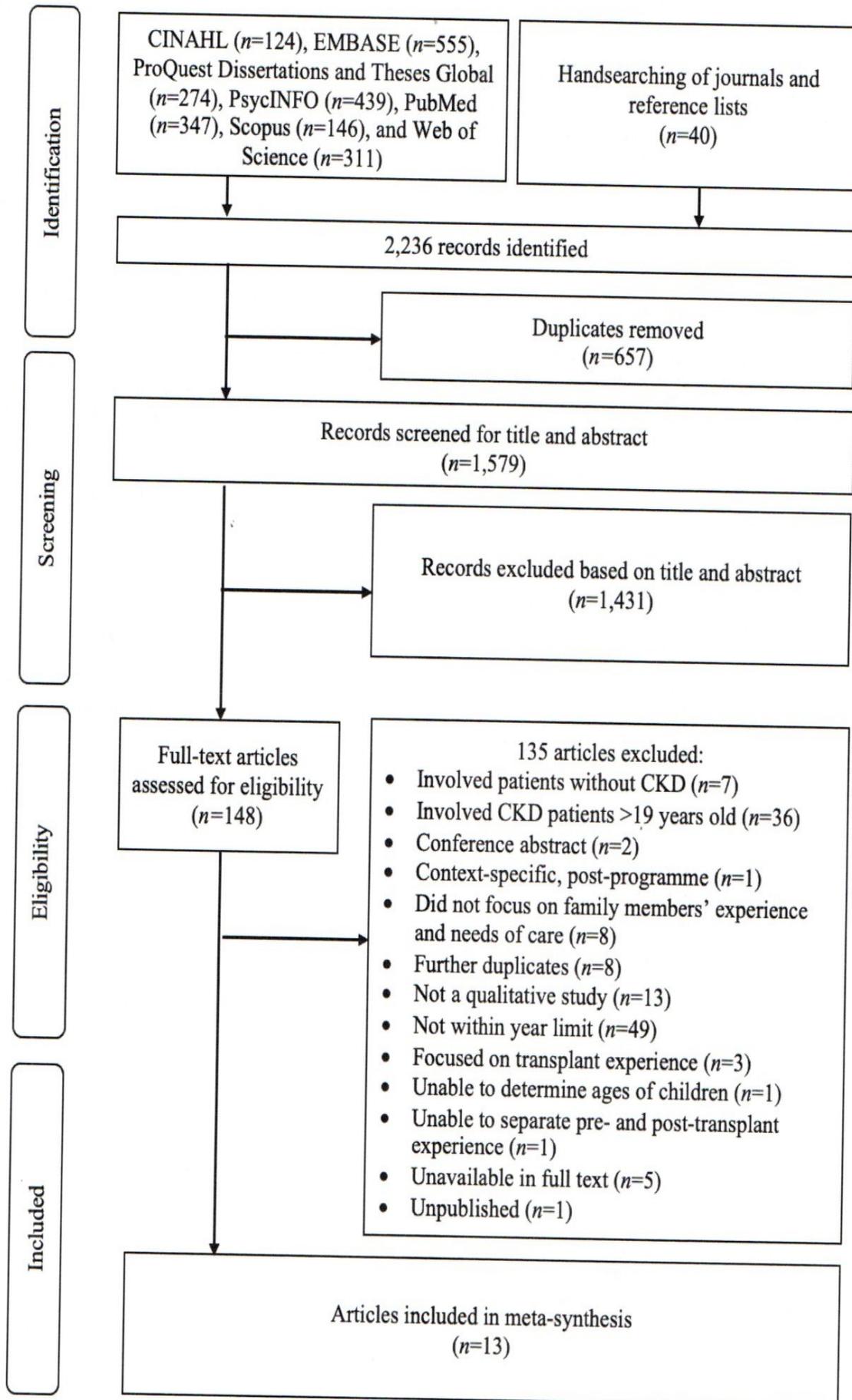


Fig. 1. PRISMA flow diagram of the study selection process.

Results

Summary of search results

Three authors were contacted for additional data and two responded. The results of the screening process, including reasons for exclusion, have been presented using the PRISMA flow diagram in Fig. 1 (Moher et al., 2009).

Characteristics of included studies

Studies were published from 2010 to 2020 across eight countries (Fig. 2). Beanlands et al. (2017) was conducted in both Canada and United States. Qualitative descriptive ($n = 7$), hermeneutic phenomenology ($n = 2$), grounded theory ($n = 2$), and qualitative interpretive ($n = 2$) methodologies were used to explore experiences and needs of care. Purposive sampling ($n = 11$), semi-structured interviews ($n = 9$), and thematic analysis ($n = 7$) were adopted by most studies. Studies involved family members caring for children and adolescents whose ages reportedly ranged from 0 to 19 years old. Although all stages of CKD were covered. Majority involved diagnoses of at least stage 3 CKD. Family members ($n = 280$) included fathers ($n = 83$), mothers ($n = 190$), siblings ($n = 5$), and grandparents ($n = 2$). Details are found in Table 1.

Quality appraisal

Studies scored at least 24/30 in terms of quality and inter-rater agreement was approximately 77%. Quality appraisal results for eligible studies are summarized in Appendix D.

Themes and subthemes

Three themes emerged from the meta-synthesis (Table 2). The effect size of each theme amounted to approximately 85%, 86% and 54% respectively. Details of extracted quotes for each theme and subtheme may be found in Appendix E.

Demands of caregiving

The nature of pediatric CKD caregiving entailed complexities and multidimensional repercussions on families involved. The necessary

adoption of the caregiver role introduced changes experienced through demands from medical management, uncertainty and unpredictability, personal sacrifices and losses, and disruptions to family dynamics.

Medical management

Family caregivers held responsibility for enforcing medication compliance, diet and fluid restrictions in their childrens CKD management. However, these were often met with strong resistance by children.

“... when first ill she was an absolute bloody nightmare! ... would take two or three of us to hold her down and get it [medicine] in” (Mother) (Swallow et al., 2011, p. 519)

Some parents were at a loss as they expressed feeling conflicted between fulfilling the role of a parent and denying children of their basic needs and wants due to intake restrictions (role of caregiver), resulting in guilt and heartbreak.

“I feel bad and guilty. ... Its hard to be saying no all day, and you feel [like] the worst mom ever because they told you that” (Mother) (Wightman et al., 2019, p. 8)

Learning new skills and familiarizing with medical equipment for home-based procedures were challenging for parents to get accustomed to. Apart from fulfilling familial and societal roles, the grueling medical role required time and constant effort, leaving some parents feeling overwhelmed and drained.

“We have to be a nurse, we have to be a parent, we have to do a lot of things that we are not accustomed to do to a normal child. So... you're stressed out, there's no doubt about it. We have to work hard in order to bring home money. When we come home we have a child who is sick in the night (and) she has to go on dialysis. She cries on and off, and we have to get up and attend to her and make sure she is okay. ... Life is tough.” (Father) (Nicholas, 2017, p. 5).

Transport to and from treatment centers, medication bills and treatment costs proved to be expensive, causing financial strain for some caregivers and compelling frugality.

“You've got to think twice before you go and spend—well I do before I spend on anything...even basic clothes.” (Mother) (Medway et al., 2015, p. 388)

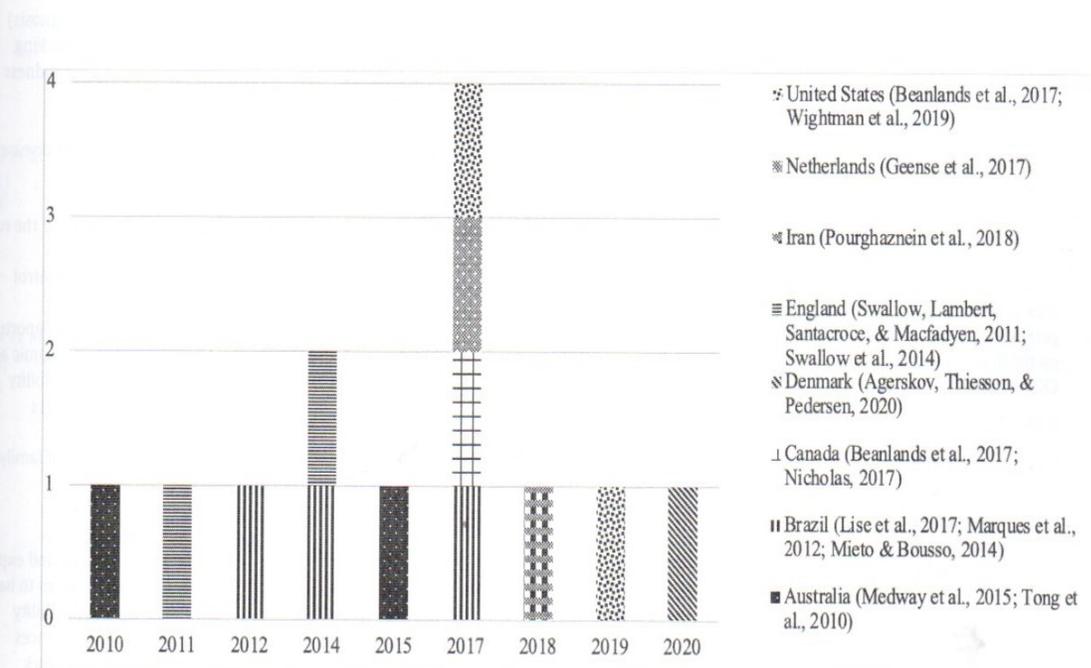


Fig. 2. Country distribution of included studies.

Table 1
Characteristics of included studies.

Author (Year)/ Country	Aim	Methodology (Study design/ sampling/ data collection/ data analysis)	Sample size and characteristics of key informants	Demographics of children and adolescents with CKD	Findings
Agerskov et al. (2020) Denmark	To explore experiences and the significance of relationships and dynamics among family members living with a child with ESKD	Hermeneutic phenomenology Purposive sampling Semi-structured individual interviews Narrative analysis	Fathers (7) Mothers (7) Siblings (5) Children with CKD (5)	Age: ≤18 years old CKD staging: 4 or 5 Treatment: unspecified (7)	1. The significance of close relationships a. Sharing the sun and wind equally b. Dealing with a sense of belonging 2. The importance of having relations outside the nuclear family a. The unique support from grandparents b. Contact with the health professionals and other adults c. The importance of support from friends
Beanlands et al. (2017) United States and Canada	To explore patient and parent perspectives on learning needs related to nephrotic syndrome (NS)	Qualitative descriptive Purposive sampling Semi-structured focus groups and individual interviews Content analysis	Fathers (7) Mothers (18) Adult patients (22)	Age: 3–16 years old CKD staging: NS <1–4 years Treatment: unspecified	1. Understanding the diagnosis and approach to treatment a. Getting a diagnosis b. Understanding NS c. Knowing what to expect d. Learning about medications 2. Learning to manage NS a. Tracking/ monitoring b. Knowing what to look for c. Preventing and managing relapse d. Managing medications and side effects e. Diet 3. Getting the right information a. Understandable b. Individualized c. Accurate d. Credible e. Timely
Geense et al. (2017) Netherlands	To describe the parents' support needs regarding the problems they experience in having a child with CKD	Qualitative descriptive Purposive sampling Focus group interviews Thematic analysis	Fathers (5) Mothers (16)	Age: 8 months - 17 years old CKD staging: 1–5 Treatment: pre-dialysis (12), dialysis (5) and transplant (3)	1. Information needs a. Child's CKD b. Child's medication c. Child's diets d. Own work and hobbies 2. Emotional support needs 3. Practical support needs a. To hand over care b. Transportation c. Financial management d. School
Lise et al. (2017) Brazil	To understand the experience of the family caregiver of the child in conservative renal treatment	Qualitative descriptive Snowball sampling (purposive) Semi-structured interviews Thematic analysis	Mothers (11)	Age: 2 months – 11 years old CKD staging: 1–3 Treatment: Conservative renal treatment/ pre-dialysis (11)	1. Discovering the disease 2. Dealing with the disease 3. Realization of the child's health 4. Living life for the child 5. Realizing the existence of support
Marques et al. (2012) Brazil	To describe the family's experience in living with chronic renal disease in children and to verify the changes faced by the family	Exploratory qualitative descriptive Sampling method: unspecified Interview structure unspecified Collective subject discourse analysis	Father (1) Mothers (8)	Age: 2–18 years old CKD staging: ESKD Treatment: dialysis (9)	(Family's reaction of diagnosis) 1. The discovery was shocking 2. A lot of difficulty and sadness (Experience) 1. A new experience 2. There are cases of this disease in the family (Changes in routine) 1. Everything has changed the routine and in our lives
Medway et al. (2015) Australia	To describe the experiences, perspectives, and beliefs of parents caring for children on the financial impact of CKD	Grounded theory Purposive sampling Semi-structured individual interviews Thematic analysis	Fathers (5) Mothers (22)	Age: 6–18 years old CKD staging: 3 to 5 Treatment: dialysis (6), kidney transplant (14) and unspecified (6)	1. Loss of freedom and control a. Prioritizing care b. Limiting occupational opportunities c. Appreciating socioeconomic advantage 2. Burden of sole responsibility a. Inability to rely on others b. Lack of respite c. Increased separation of family roles d. Self-reliance 3. Adapting for survival a. Vigilant budgeting b. Redefining normality and expectations c. Rechanneling resources to basic needs d. Negotiating work flexibility 4. Instability of circumstances a. Depleted capacity to work b. Unpredictability of child's health

Table 1 (continued)

Author (Year/ Country)	Aim	Methodology (Study design/ sampling/ data collection/ data analysis)	Sample size and characteristics of key informants	Demographics of children and adolescents with CKD	Findings
					<ul style="list-style-type: none"> c. Burden of travel-related costs d. Imposition of debt e. Domestic upheaval 5. Struggle in seeking support <ul style="list-style-type: none"> a. Falling through the cracks b. Unmet information needs
Wetto and Bousso (2014) Brazil	To understand the mothers' experience of following their children on hemodialysis and provide theoretical support for planning care that meets their real needs	Grounded theory Theoretical sampling Data collection: type of interview unspecified Constant comparison analysis	Mothers (11)	Age: ≤18 years old CKD staging: ESKD Treatment: hemodialysis (n = unspecified)	<ul style="list-style-type: none"> 1. Having life imprisoned by a machine <ul style="list-style-type: none"> a. Suffering the impact with the existence of hemodialysis b. Feeling powerless 2. Giving meaning to hemodialysis <ul style="list-style-type: none"> a. Incorporating everyday care b. Needing to have the courage to face reality c. Strengthening with the interactions d. Waiting for a new kidney
Nicholas (2017) Canada	To examine the roles and experiences of fathers of children with chronic kidney disease	Qualitative interpretive Purposive sampling Semi-structured interviews Thematic analysis	Fathers (22)	Age: 1–18 years old CKD staging: unspecified Treatment: predialysis (4), hemodialysis (6), peritoneal dialysis (4) and transplant (8)	<ul style="list-style-type: none"> 1. Fatherhood roles 2. Adjusting to CKD 3. Isolation 4. Nuanced differences between CKD treatment modalities 5. Action orientedness, remaining positive and moving forward
Pourghaznein et al. (2018) Iran	To explore Iranian mothers' perspectives regarding hemodialysis treatment for their children	Hermeneutic phenomenology Purposive sampling Semi-structured interviews Thematic analysis	Mothers (11)	Age: 5–15 years old CKD staging: ESKD Treatment: hemodialysis (n = unspecified)	<ul style="list-style-type: none"> 1. Mother enclosed by child care <ul style="list-style-type: none"> a. Overwhelming care b. Exhausting commutes c. Hemodialysis as a prison for mother and child d. The mother as the only caregiver e. Social limitations 2. Emotional and psychological tension <ul style="list-style-type: none"> a. Alternating between hope and hopelessness b. Endless concerns c. Agony and sorrow d. A sense of neglect e. A mother's desperation 3. Acceptance and contrivance <ul style="list-style-type: none"> a. Tendency towards the spiritual b. Patience and management 4. The entire family being a victim of a sick child <ul style="list-style-type: none"> a. Marital relationships problems b. Restrictions on fun and family relationships c. Undermining the economic situation of the family d. Other children being sacrificed 5. Self-devotion <ul style="list-style-type: none"> a. Emotional insulation b. Melting in the child's body
Swallow et al. (2011) England	To obtain and compare fathers' and mothers' accounts of managing long-term kidney conditions	Qualitative interpretive Purposive sampling Individual and joint semi-structured interviews Framework analysis	Fathers (14) Mothers (14)	Age: 0–17 years old CKD staging: unspecified/omitted Treatment: unspecified	<ul style="list-style-type: none"> 1. Skill development <ul style="list-style-type: none"> a. Processing large amounts of information b. Sharing/negotiating caregiving c. Restraining children d. Adapting to treatment regimens e. Communicating
Swallow et al. (2014) England	To explore the views of parents, patients and professionals on the types and forms of information they would like included in the online parent information and support (OPIS) application for parents of children with CKD stages 3–5	Descriptive qualitative Purposive sampling Individual and/or group semi-structured interviews Framework analysis	Fathers (9) Mothers (23) Children with CKD (26) Multi-disciplinary team (12)	Age: 0–19 years old CKD staging: 3–5 Treatment: Unspecified	<ul style="list-style-type: none"> 1. Clinical care-giving information <ul style="list-style-type: none"> a. Information on CKD and treatment regimens b. Videos containing CKD-specific information c. CKD specific, educational cartoons/puzzles d. Question and answer area 2. Psychological support for care-giving <ul style="list-style-type: none"> a. Social-networking b. Managing stress c. Enhancing families' health-care experiences d. Family case-studies

(continued on next page)

Table 1 (continued)

Author (Year)/Country	Aim	Methodology (Study design/ sampling/ data collection/ data analysis)	Sample size and characteristics of key informants	Demographics of children and adolescents with CKD	Findings
Tong et al. (2010) Australia	To explore how CKD affects parental caregivers during all stages of CKD	Qualitative descriptive Purposive sampling Structured interviews Thematic analysis	Fathers (9) Mothers (19)	Age: 0–19 years old CKD staging: 1–5 Treatment: predialysis (5), hemodialysis (2), peritoneal dialysis (1) and transplant (12)	1. Absorbing the clinical environment a. Confronting the diagnosis b. Invasive procedures c. Conflict and trust d. Varying quality of care e. Losing ownership f. Jeopardising relationship with staff 2. Medicalizing parenting a. A consuming routine b. Pressure and isolation c. Struggle with feeding d. Medical management e. Psychological trauma 3. Disrupting family norms a. Spousal tension and dependency b. Sibling neglect c. Household and financial stress d. Decision to donate e. Social restriction 4. Coping strategies and support structures a. Internal coping strategies b. External coping strategies c. Information needs
Wightman et al. (2019) United States	To describe the experience of parental caregivers of children receiving chronic dialysis for end-stage kidney disease	Qualitative descriptive Purposive and convenience sampling Semi-structured interviews Thematic analysis	Fathers (4) Mothers (30) Grandparents (2)	Age: 0–19 years old CKD staging: ESKD Treatment: hemodialysis (24) and peritoneal dialysis (11)	1. Caregiver medicalization a. Diagnosis and initiation b. Disease management c. The future 2. Emotional adjustment a. Initial and/or acute phase b. Acceptance c. Personal growth d. Medical stress and psychological burden 3. Pragmatic adaptation a. Disruption b. Adaptation of life goals and/or sense of self c. Financial impact 4. Social adjustment a. Relationship opportunity b. Advocacy c. Relationship risk d. Family functioning e. Intimate relationships

Uncertainty and unpredictability

It was difficult to deal with the unpredictability of the child's condition as there was no guarantee of the rate of CKD progression. Kidney transplants involve long waiting lists with precarious outcomes, contributing to constant uncertainties in the child's future and of caregiving without any sight of freedom from CKD. The little control over CKD made it difficult to plan for the future and gave rise to stress and frustration.

"It sucks. We've got a long time before she gets put on the transplant list, and then transplant isn't the end of it all. Even after that, things can go wrong" (Family caregiver) (Wightman et al., 2019, p. 8)

"It's [son's condition] a bomb ticking away in the background. ..." (Father) (Swallow et al., 2011, p. 518)

Personal sacrifices and losses

The tremendous effort required for CKD management necessitated sheer dedication towards the caregiver role. Priorities shifted with less time, energy and freedom for other commitments. Many caregivers,

often mothers, felt compelled to divert attention from their jobs and sacrifice a source of income to be more physically present for the sick child.

"My husband was trained to do the dialysis, he could do it, but he didn't do it nearly as much, because we'd say well, it's better for one of us to put a hundred per cent in at work than two of us to put in fifty per cent at work. It just works better." (Mother) (Medway et al., 2015, p. 388).

The circumstances of caregiving pushed families to forgo leisure activities and relaxation. It was difficult to dedicate time to maintain existing relationships or nurture new ones within and outside the family. Parents sacrificed precious time with siblings of sick children, causing them to feel neglected. Spousal relationship was also strained when some parents argued and drifted apart due to the weight of caregiving.

"Hey, let's take a break, it's the summertime; ..., and let's not come back until Saturday.' ... We were a water-park family, so we would visit water parks all the time. We miss those things" (Family caregiver) (Wightman et al., 2019, p. 9).

Table 2
Themes and subthemes.

Themes	Subthemes
Demands of caregiving	<ul style="list-style-type: none"> • Medical management • Uncertainty and unpredictability • Personal sacrifices and losses
Support systems	<ul style="list-style-type: none"> • Adaptive coping • Information needs • Emotional and psychosocial needs • Practical needs
Defining and making sense of new reality	<ul style="list-style-type: none"> • Unwanted catastrophe • A silver lining

"Then mum and dad were really attentive to him (the sick sibling), and I felt that they forgot about me a lot." (Sibling) (Agerskov et al., 2020, p. 991).

"... my husband is both nervous and bored. My relationship is very cold" (Mother) (Pourghaznein et al., 2018, p. e23).

Support systems

To meet the demands of caregiving, some families channeled self-support through adaptive coping behaviors. Families expressed external support was lacking to meet their information, emotional, psychosocial and practical needs of caregiving.

Adaptive coping

Families gradually adopted acceptance towards having a child with CKD which drove them to adapt to new changes and eased moving forward realistically with their care. Families also gathered strength and found comfort in being optimistic about their situation and their child's future.

"You don't, 'why me, what happened here?' I don't think that way ... What can be done, what are our options, our choices and let's make some decisions and let's do the best thing so he can lead a healthy and long life." (Father) (Nicholas, 2017, p. 5).

"There's always someone worse off and to be honest that's what keeps you going." (Parent) (Tong et al., 2010, p. 555).

"I think we're really good at just focusing on the benefits and just realizing that, like, well who cares about the burden? Because the benefit is that she's alive and feeling good....So we try not to make it a burden." (Family caregiver) (Wightman et al., 2019, p. 8).

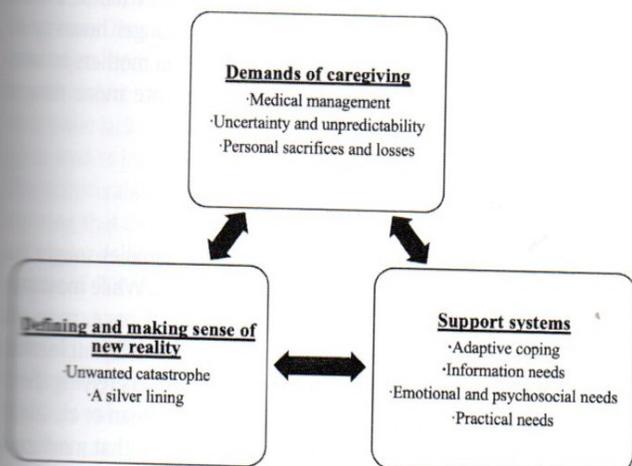


Fig. 3. Thematic diagram of themes and subthemes.

Information needs

Being inexperienced with pediatric CKD caregiving, families struggled to make informed decisions with incomplete information. Most caregivers preferred receiving sufficient details from HCP to understand the full picture of CKD, its treatment options and available caregiver assistance services.

"It would be efficient if you could get all the pros and cons of your choices and possibilities. It enables you to make the decisions more easily" (Father) (Geense et al., 2017, p. 833).

Yet, some caregivers were overwhelmed when too much information was presented all at once.

"When I took [child] in there they said we're gonna try these medications, if that don't work we're going to dialysis, if that doesn't work kidney transplant. I was like whoa....Let's slow down and do...some baby steps as we go." (Parent) (Beanlands et al., 2017, p. i103).

The way information was delivered was also important as families valued definite terms, honest and relevant answers.

"... they were honest with us, I think that's what counts the most." (Parent) (Tong et al., 2010, p. 551).

"... I think parents cling to those words, like 'think' or 'maybe.' Those qualifying words. I like the very concrete if you know it" (Family caregiver) (Wightman et al., 2019, p. 7).

Emotional and psychosocial needs

The demands of caregiving built negative emotions, but caregivers lacked avenues for cathartic release. There were caregivers who expressed disappointment with the services provided by the medical team as they hoped HCP could do more to lend a listening ear by proactively providing more compassion and attention to their well-being.

"I come here and sit for four hours. No one speaks with me. Nurses only connect the machine to my child without asking, 'Are you okay?' I like having someone to speak with" (Mother) (Pourghaznein et al., 2018, p. e22).

Caregivers also felt isolated by extended families and friends who generally lacked empathy as they could not relate to their experiences. Loneliness and exasperation brewed from needing but lacking external family and friends to confide in.

"They don't know how to discuss or what questions to ask, so they just kind of avoid" (Family caregiver) (Wightman et al., 2019, p. 10).

"Sometimes we get up at night and we just cry to the wall. Who will listen, who will care, do you know what I mean?" (Father) (Nicholas, 2017, p. 4).

For some, the nuclear family could provide emotional support as spouses relied on each other to overcome hardships. Joining support groups with other families battling pediatric CKD was also well-received and helpful as shared identity brought company and encouragement.

"When things are tough, I know 100% that I can rely on [my wife], and she knows 100% she can rely on me. ... the 2 musketeers, the 2 of us, supporting one another" (Family caregiver) (Wightman et al., 2019, p. 11).

"...would be really useful for parents to have a social network with other parents to talk about the stress of managing the condition with people that know" (Mother) (Swallow et al., 2014, p. 7).

Practical needs

Having any extra pair of hands for practical help from family and friends was usually welcomed. This was not limited to CKD caregiving tasks but extended to simple favors such as helping with chores. Albeit temporary, they appreciated the help offered as it allowed some time for much-needed respite.

“There's no one that can wear our shoes for a night and there's no break or anything like that. So, respite care would definitely be something that would be I think beneficial to all parents, especially when it's been a long time without a break from it.” (Mother) (Medway et al., 2015, p. 388).

Yet, some mothers were reluctant to initiate requests for practical support unless it was necessary as they refused to burden others. This was especially so regarding financial help.

“Financial not so much [support]. Because you feel funny, ... you don't want to be grabbing from people all the time. ... they would help, but it's us that feel guilty to ask. Which we don't ask.” (Mother) (Medway et al., 2015, p. 388).

Some mothers also did not trust others to care for their own child and felt more assured if they provided the care personally.

“She [mother in law red.] really wants to learn how to handle the feeding pump. However, she is not really clever, and I'm scared she would blow him [child red.] up” (Mother) (Geense et al., 2017, p. 835).

Defining and making sense of new reality

Upon receiving the diagnosis, the lives of these families took an abrupt turn and their overall experiences as caregivers shaped new meanings of reality.

Unwanted catastrophe

Initially, shock and disbelief were commonly felt from the unanticipated news. Families could not understand how the disease manifested silently and were indignant at having to endure suffering. There was devastation and many viewed livings with CKD negatively as their world seemed to have crumbled.

“To hear was a thud, a big shock for the whole family, seemed to discover that the world was falling apart” (Parent) (Marques et al., 2012, p. 1341).

“It hasn't really been easy for us at all. And there's times when you then think, oh god, why me” (Mother) (Medway et al., 2015, p. 389).

A silver lining

As they grapple with the sudden catastrophe, some families gradually found their silver lining. Having undergone the ordeal, their experiences brought revelations and invaluable lessons. Perspectives changed as some caregivers grew to be more appreciative and no longer took things for granted.

“I think it's opened up all of our eyes to other people's challenges and taking a step back and not judging people. ... It made me slow down my life and I guess appreciate more what you have versus just being so wrapped up in everything else” (Family caregiver) (Wightman et al., 2019, p. 8).

Being a caregiver also provided opportunities for building caregiver-child relationships by allowing families to spend more time with the sick child and develop closer bonds.

“I think it brought us closer [because] she needed me not as just a parent but as care provider” (Family caregiver) (Wightman et al., 2019, p. 11).

Discussion

Overview

Findings of this review showed that family members caring for young CKD patients experienced highly demanding caregiver roles due to overwhelming challenges associated with medical management, stress from uncertainties and unpredictability and obligatory sacrifices. Adaptive internal coping skills, support groups, and spousal support were some ways to cope with the demands but many still expressed having insufficient external resources to support their caregiving needs. Sustained suffering led many to view CKD as a catastrophe but some managed to uncover blessings along the way.

Application of FAAR model

The dynamic relationships between caregiving demands, support systems, and perceived meanings that reflected families' experiences and needs may be explained by the FAAR Model (Fig. 3). The model posits that family systems constantly work to sustain balanced functioning by changing the level of demands (stressors and strains), utilizing capabilities (coping behaviors and resources) or altering the interpretations of their reality (Patterson, 1988; Patterson & Garwick, 1994). Once factors are in equilibrium, optimal outcomes will be reflected in preservation of the family unit, proper role functioning and better physical and mental health outcomes (Patterson & Garwick, 1994). However, the experiences of participating families demonstrated disequilibrium as the overwhelming demands of caregiving exceeded their capabilities for proper adjustment.

Demands

The complicated and stressful nature of CKD management, needs, emotional, and psychosocial impact on caregivers were generally consistent with reviews by Tong et al. (2008). Families' experiences were indicative of high caregiver burden and this was expected of caregivers of children with chronic illnesses (Piran et al., 2017). Similar to Aldridge (2008) and Lomba et al. (2014), mothers spent more time with children, engaged in more physical care and were identified as the main caregiver for their sick children more than fathers. Some mothers were more likely to sacrifice their jobs to focus on immense caregiving roles whereas fathers retained the responsibility of providing income for the family. It suggested mothers may be more involved in direct caregiving duties as traditional gender roles in society that recognize childcare as a women's responsibility may still somewhat be a social norm. This was reinforced when fathers worked longer hours or received a higher salary, putting a realistic pressure on mothers to sacrifice their own jobs and enabling them to dedicate more time to childcare (Raley et al., 2012).

Support needs and meanings

When demands of caregiving were extensive, families sought balance through adaptive coping and external resources. While most caregivers preferred receiving as much information at once, some felt overloaded and needed information in parts due to different learning needs. Only two studies reported instances of caregivers relying specifically on religion (Pourghaznein et al., 2018; Wightman et al., 2019). This finding contrasted with the possible expectation that more caregivers may turn to religious coping in view of the widely reported benefits of religion on improved coping and health outcomes in those

dealing with chronic illnesses (Rathier et al., 2015; Roger & Hatala, 2018). However, this may be due to potential biases in which the pool of participants from the included studies were mostly non-religious or less reliant on their faith as a coping strategy. Caregivers also seemed to value empathy and support from others. This could be viewed as a normal human response pushed by the need for a sense of belonging and desire for meaningful social connection (Cacioppo & Patrick, 2008). Having insufficient informational, emotional, and psychosocial support to successfully counter the overwhelming demands of caregiving caused demands to exceed capabilities. This state of disequilibrium caused families to interpret their situation as a catastrophe which heightened their perception of caregiving burden and fueled caregiver stress (Toledano-Toledano & Domínguez-Guedea, 2019). Yet, some managed to develop appreciation and gratitude amidst the struggle. This could be explained by post-traumatic growth in which positive psychology emerges from difficult life circumstances (Tedeschi et al., 2018). For families to adapt and restore equilibrium, there is a need to increase their capabilities, decrease their demands or change their meaning of the situation (Patterson & Garwick, 1994). This is where nursing interventions can provide support to increase coping capabilities to lighten their load and make caregiving seem less daunting.

Strengths and limitations of the review

This review presented more recent caregiver experiences on extensive treatments modalities prior to kidney transplant and covered all CKD stages. This is meaningful as kidney dysfunction in pediatric CKD is a continuum, making it imperative to understand the family's caregiving experience across all stages. The meta-synthesis approach also helped generate deeper insights and meaning on the topic (Edwards & Kaimal, 2016). Gaps in existing practices and support systems were highlighted. By demonstrating inter-related aspects of caregiving, purposeful interventions may be shaped to improve pediatric CKD caregiving experience for families.

However, findings are more representative of parents' ($n = 273$) experiences and needs since they formed the bulk of key informants. These insights are less generalizable for siblings ($n = 5$) and grandparents ($n = 2$) due to the lack of primary studies on these family members. Much information is still required to facilitate family-centered support and care.

None of the studies described ADHD, anxiety, depression, parenting style, socioeconomic status, catastrophizing or family functioning of participating caregivers, all of which are also important confounders that may shape caregivers' experience. Only 5 out of 13 studies briefly described caregiver literacy in terms of educational attainment that ranges from being illiterate to having a degree (Lise et al., 2017; Wedway et al., 2015; Pourghaznein et al., 2018; Swallow et al., 2011; Wightman et al., 2019). However, in view of their respective aims, results of these studies were not analyzed in relation to literacy levels of caregivers. Therefore, there is a lack of understanding on how different education levels of caregivers may influence the experience of caregiving for children with CKD. Findings embodied heavy Western influence due to the lack of primary studies conducted in Asia and having only English studies included due to limited resources for language translation. The transferability of findings to the Asian context may be limited considering that differences in culture across countries may shape experiences, needs and meanings differently (Nilchaikovit et al., 1993). Yet, results of this review showed that families generally faced similar challenges and needs despite having possible differences in cultural or economic backgrounds.

The 10-year limit imposed to gather recent and relevant information had somewhat limited the overall understanding of developments in families' caregiving experience of pediatric CKD. Viewpoints were only presented from a fragment in time as some valuable studies before 2010 were not analyzed.

Implications and recommendations for future research

Knowledge of these experiences and needs of family members raises awareness of the challenges of pediatric CKD caregiving and gaps in support systems. The implication to nursing education comprises of shaping effective communication training for more compassionate interactions between nurses and families of children with CKD to deliver more psychosocial support. In clinical practice, it encourages nurses to apply an individualized approach to caregiver education with honest and concrete information. Nurses may engage in inter-disciplinary collaboration to link caregivers to pediatric CKD caregiver support groups. By facilitating the development of more targeted family support interventions to alleviate their caregiver burden, family members may cope better and provide greater quality of care, ultimately improving patient outcomes (Kokorelias et al., 2019).

The low numbers of siblings and grandparents presented a dearth of information for understanding their experiences and needs. Their voices matter as their lives are very much intertwined with children with CKD. It is recommended to conduct more primary qualitative studies to explore the impact they face. This may aid the development of HCP education, policies or individualized interventions that may support families better. Exploring and identifying the effects of pre-existing confounders on caregivers' experiences and needs may also help HCP recognize, anticipate and provide aid to the groups of caregivers that may require more support.

Future research may explore family caregiving for children with CKD in Asia to compare differences from Western cultures with different healthcare policies. This may be helpful in providing more region-specific references for caregivers and HCP. It may also be interesting to forsake year limits to learn how the field of pediatric CKD has progressed for families over the years.

Conclusion

Exploring the experiences and needs of families caring for pediatric CKD revealed mostly negative experiences of caregiving and lack of supporting resources to effectively cope with the highly demanding role. By unveiling the gaps in their needs, it is hoped that more targeted strategies may be put into place to provide families with sufficient support to reduce their burden of care.

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Declaration of Competing Interest

The authors have declared no conflict of interest.

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Appendix A. Supplementary data

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