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Sources of Distress Experienced by Parents of Children with Chronic Kidney Disease on Dialysis: A Qualitative Systematic Review

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ABSTRACT

Problem: Parents of children with chronic kidney disease face tremendous burdens of care, having to adopt dual roles as parents and informal healthcare providers, delivering home-based clinical care, despite lacking proper qualification and training.

Eligibility criteria: A systematic review of qualitative studies was conducted to identify sources of distress among parents caring for children with chronic kidney disease undergoing dialysis, excluding children who have had renal transplants. Guided by PRISMA guidelines, six electronic databases (PubMed, Embase, PsycINFO, Scopus, Cochrane, Google Scholar) were searched for relevant articles published in English. A three-step inductive thematic synthesis method outlined by Thomas and Harden (2018) was used to form descriptive themes and the Critical Appraisal Skill Program (CASP) qualitative checklist was utilised to appraise the quality of included articles.

Sample: A total of 23,129 title and abstracts were reviewed; 161 full texts were reviewed. Thirteen papers, with the experiences of 183 parents, met the inclusion criteria. Most included studies were conducted in Western countries, which may limit the applicability of this review to other countries.

Results: Five themes emerged: disease-related distress, personal struggles, family structure, lack of resources and unrealistic social expectations.

Conclusion: Parents of children with chronic kidney disease undergoing dialysis experienced distress at multiple levels.

Implication: Healthcare professionals caring for children with chronic kidney disease could screen parents early for distress, and refer them to relevant psychosocial and community services.

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Introduction

The use of dialysis in pediatric patients with chronic kidney disease (CKD) remains a core pillar for renal replacement therapy (RRT) with persisting scarcity of kidney transplants. Two thirds of all cases of CKD arise from congenital abnormalities and hereditary nephropathies (Harambat, van Stralen, Kim, & Tizard, 2012). Dialysis, however, creates

a complicated treatment relationship between children and their parents. As their children's main caregivers, parents face tremendous burdens of care. They need to adopt dual roles of parents and informal healthcare provider, delivering home-based clinical care and nutritional supports, and monitoring symptoms, despite lacking professional qualification and training (Tong, Lowe, Sainsbury, & Craig, 2008). This constant pressure often causes psychological distress among parents.

The pressure of a parental role in caring for children with CKD can severely affect their mental wellbeing, resulting in higher levels of anxiety (de Paula, Nascimento, & Rocha, 2008), depression (Tsai, Liu, Tsai, & Chou, 2006), marital strain (de Paula et al., 2008; Laakkonen, Taskinen, Ronnholm, Holmberg, & Sandberg, 2014), and financial burden (Cimete, 2002; Medway et al., 2015; Tong, Lowe, Sainsbury, & Craig, 2010). Eleven years ago, Tong et al. (2008) conducted a systematic review on

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parental experiences in caring for pediatric patients with chronic kidney failure. We thus sought to perform an updated review to identify sources of distress among parents caring for children with CKD specifically undergoing dialysis and to identify sources of parental distress that could potentially be alleviated.

Methods

Search strategy

A systematic review of qualitative studies was conducted using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). A qualitative synthesis allows for the generation of rich interpretation and understanding of the impact of a condition, allowing for a deeper understanding of parents' perspectives on their sources of distress (Flemming, Booth, Garside, Tunçalp, & Noyes, 2019). Electronic Database search was run without time limits until 20 December 2019 on six databases (PubMed, Embase, PsycINFO, Scopus, Cochrane, Google Scholar) as we wanted to include all the available literature on the phenomenon of interest. The search strategy was developed in conjunction with a medical librarian (Appendix 1) and only peer-reviewed articles published in English were included. The search study included text words and MeSH and keyword terms for chronic kidney disease, caregivers/parents and children. Additional articles were found by hand searching the reference list of included articles. Fig. 1 shows the PRISMA flowchart of included studies.

Study selection

We included qualitative studies reporting on distress (in forms of any negative experiences including, but not limited to, psychological, physical, familial and financial hardship) expressed by parents of children undergoing chronic dialysis (peritoneal dialysis and hemodialysis). Children who had undergone kidney transplants were excluded. Studies were included if they used qualitative methods, including in-depth interviews and focus groups. Studies using mixed methods were included but quantitative results in these studies were excluded. Commentaries, editorials and systematic reviews were excluded.

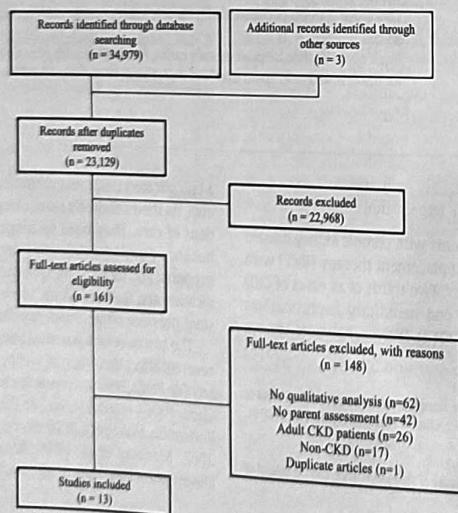


Fig. 1. PRISMA flowchart of included studies.

Citations were downloaded and managed with Endnote X9, and duplicates were removed to yield citations for sieving. Independent sieving and full text review were undertaken by three authors (Z.H.O., C.H.N. and M.K.J.X.) with discrepancies resolved with a senior author (Y.N.P.M.).

Data extraction and synthesis of results

A structured form, with journal details (author, year of publication), methodology, sample size and characteristics, and main findings, was used to extract and document data. Independent line-by-line coding was undertaken by two authors in the extraction of data from the articles. Using a three-step inductive thematic synthesis method outlined by Thomas and Harden (Thomas & Harden, 2008), transcripts of the codes were compared, contrasted and similar elements were used to form descriptive themes. Further discussions among the authors generated and refined analytical themes and provided interpretation beyond that of the primary findings. The Critical Appraisal Skill Program (CASP) qualitative checklist with the domains of aims, methodology, design and results was used to appraise quality of included articles into "good", "moderate" or "poor", as recommended by the Cochrane qualitative and implementation methods group. The results of CASP were used to enhance the rigor of synthesis (Dixon-Woods et al., 2007) and not to eliminate any studies regardless of their quality, all the studies were included in this review. The details on the quality of the included studies can be found in Supplementary File 2. The evaluation was performed by two authors with discrepancies resolved through face-to-face discussions with a third author. The discrepancies were mainly regarding the unclear methodologies and the grouping of the extracted data.

Results

The search strategy yielded 34,979 abstracts and 23,129 articles were left after removal of duplicates. After screening titles and abstracts 22,968 articles were excluded, and 161 full-text articles were reviewed. One hundred forty-eight articles were excluded for various reasons: quantitative methodology (62), no parental assessment (42), adult CKD patients (26), unrelated to CKD (17) and duplicate (1) (Fig. 1).

Table 1
Summary of included studies.

Study/country	Findings	No. of parents	Parent involved	Age range of patients (years)	Type of dialysis	Methods
Dracopoulos & Weatherly, 1983 (USA)	The problems that families of children in renal failure face involve many domains including disease-related, societal, family, parental and patient's wellbeing.	2	Mothers	NR	HD and PD	Narratives
Geense et al., 2017 (NLD)	The parents with children suffering from CKD require informational, emotional and practical support to help them better cope with caregiving.	5	Mothers	7–16	HD and PD	Focus groups
Güler Cimate, 2002 (TUR)	This study illustrated the common stress factors and coping strategies of parents whose children had been treated by hemodialysis.	31	Mothers and fathers	4.5–20	HD	Interviews and focus group discussions
Middleton, 1996 (GBR)	The analysis revealed what is commonplace in the management of the demands parents face in the difficult circumstances of their child care.	13	Mothers and fathers	NR	PD	Parent group meetings
Mieto & Bouso, 2014 (BRA)	Themes include the new demands to comprehend the new health conditions of their children and the strategies employed to endure the experience.	11	Mothers	0–18	HD	Interviews
Nicholas, 1999 (CAN)	The study described differences in meanings mothers attached to caring for a child with ESRD, which are associated with previous maternal life experiences and future expectations for mothers' life.	24	Mothers	1–18	HD and PD	Interviews
Pourghaznein, Heydari, & Manzari, 2018, (IRN)	Themes involved the mothers enclosed by child care, emotional and psychological tension, acceptance and contrivance, the entire family being a victim of a sick child, and self-devotion.	11	Mothers	5–15	HD	Interviews
Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018, (IRN)	Iranian mothers of children undergoing hemodialysis are overwhelmed by the psychological pressures that they encounter during the treatment of their children.	11	Mothers	5–15	HD	Interviews
Sampson, 1975 (USA)	The emotional and social adjustment and intra-familial alteration of interaction patterns were analysed in the study.	NR	NR	10–18	HD	Interviews
Sari et al., 2018, (IDN)	Participants shared about their response to child care, its impact on the family, their perception of changes in children while undergoing dialysis, family's support and coping strategies.	7	NR	NR	HD and PD	Interviews
Tong et al., 2010 (AUS)	Themes included the experiences of parents who have children with CKD, having to absorb the clinical environment and take on the caregiver role as well as the coping strategies and available support structures	20	Mothers and fathers	0–18	HD and PD	Interviews
Waissman, 1990 (FRA)	Analysis revealed the conditions underlying the choice of home dialysis made by doctors and the parents of children suffering from end-stage renal disease and how the decision was made.	15 families	NR	6–20	HD and PD	Interviews
Wightman et al., 2019 (USA)	Interviews revealed the range of positive to negative caregiver experiences with regards to emotional and social adjustment, pragmatic adaptation and caregiver medicalisation.	33	Mothers and fathers	0–18	HD	Interviews

HD, hemodialysis; PD, peritoneal dialysis; NR, not reported.

AUS, Australia; BRA, Brazil; CAN, Canada; FRA, France; GBR, United Kingdom; IDN, Indonesia; IRN, Iran; USA, United States of America; NLD, The Netherlands; TUR, Turkey.

Thirteen studies conducted in 10 countries fulfilled the inclusion criteria. Six studies reported on children undergoing hemodialysis (HD), one on peritoneal dialysis (PD) while six included patients undergoing both modalities of dialysis. The studies comprised of 183 parents of which both mothers and fathers were involved. The detailed characteristics of the included studies are presented in Table 1. Appendix 2 provides the summary of quality assessment of included articles.

Five themes on sources of distress experienced by parents of children with CKD undergoing dialysis were identified: (1) disease-related distress, (2) personal struggles, (3) family structure, (4) lack of resources and (5) unrealistic social expectations. Subthemes are summarised in Table 2.

Disease-related distress

CKD serves as a significant stressor for parents from the revelation of diagnosis, the treatment process to the prognosis of the disease.

Diagnosis

Parents described having felt strong emotions when the diagnosis was first revealed to them - that the situation was incredulous and overwhelming (Tong et al., 2010). A few of them resented the fact that they were not given the diagnosis in a private setting (Tong et al., 2010). The unexpectedness of diagnosis was hard for many to handle, especially if there were no past history of renal diseases recorded by other doctors (Sampson, 1975).

Treatment

Parents reported that the various procedures and treatments undertaken on their child was heart-breaking to witness (Mieto & Bouso, 2014; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Tong et al., 2010; Waissman, 1990). Some were faced with emotional challenges when giving medications to their child due to their negative perception about medications and worry about adverse effects (Geense, van Gaal, Knoll, Cornelissen, & van Achterberg, 2017). Parents were also under the constant pressure of potential blame for potential complications while carrying out their duty of care, especially with at-home procedures like peritoneal dialysis (Tong et al., 2010).

Table 2
Summary of themes.

Disease-related distress	Diagnosis Treatment A long road ahead
Personal struggles	Physical exhaustion and poor job security Psychosocial distress
Family structure	Inability to care for other children Strain on marriage Tensions within family
Lack of resources	Formal support Informal support Unprepared for change
Unrealistic social expectations	Stigmatisation of caregivers Discrimination of child

"It feels like I am poisoning my own child"
 ((Geense et al., 2017))

Parents worried that they might not be providing adequate care for their children, especially with the complexity of care required and the expectation to deal with unforeseen events that arise during treatment (Middleton, 1996; Pourghaznein, Heydari, & Manzari, 2018; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018).

"I must take care of the fistula on her hand. She should take her medications on time. She needs to drink a little water and not consume certain foods. In sum, I am always mentally engaged, and I always think about the things that she should or should not have and whether there is pressure on the fistula of her hand?"
 ((Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018))

Liquid and dietary restrictions are instrumental components to CKD management and many parents found difficulty with compliance from their children (Cimete, 2002; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018). They felt exceedingly guilty when withholding liquid from their children and struggled with enforcing these restrictions and explaining its rationale to them (Cimete, 2002; Dracopoulos & Weatherly, 1983; Pourghaznein, Heydari, & Manzari, 2018; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Tong et al., 2010; Weissman, 1990).

"He was vomiting and retching, it just breaks your heart. You really thought they were going to die. He ended up wanting to have showers all the time, morning, noon and night. He was putting his tongue out to get the water."
 ((Tong et al., 2010))

A long road ahead

Families had to deal with the realisation that CKD is a lifelong condition and that they might never regain their sense of normality again (Dracopoulos & Weatherly, 1983; Tong et al., 2010). With the myriad of potential complications that comes along with the disease and treatments, a predictable future was deemed an impossible dream by parents. Many parents struggled to cope with this fact – they were unable to see their child's future beyond receiving a kidney transplant (Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Wightman et al., 2019).

"When we think ahead a little about the future, my brain seems to stop working. I am not certain about my child's fate. Even after the transplant, he is likely to reject the organ. If his body accepts the organ, he needs to take a lot of medications and deal with other problems."
 ((Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018))

Compared to their peers, children with CKD were often smaller and less physically able (Cimete, 2002). This observable difference brought misery to both parents and children (Cimete, 2002).

"When we are inside the hospital, I don't notice my child's growth regression, he is in the situation as with the other children. However, at home I compare with his healthy peers and understand his regression. Looking at the older ill children I know that in the future my child too will be as them and I feel miserable."
 ((Cimete, 2002))

Some parents lost faith in being able to find a renal transplant for their child (Cimete, 2002). Sometimes, they alternated between optimism and hopelessness (Cimete, 2002; Pourghaznein, Heydari, & Manzari, 2018; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018).

"I do everything with despair. There is no improvement. I have heard that those who received transplants were freed of the misery of

hemodialysis treatment. It is a ray of hope for me, but there are two children in this department who received organs and rejected them. I may lose hope again."
 ((Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018))

The fear of impending death of their child was a major source of misery for parents, which was periodically triggered by the death of their children's peers with the same disease (Dracopoulos & Weatherly, 1983; Mieto & Bouso, 2014; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018).

"Each moment, I think I am losing my son. As I sleep at night, I wake up with lots of anxiety."
 ((Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018))

Personal struggles

Physical exhaustion and poor job security

Parent had to spend most of their day and energy on their child undergoing dialysis, which is an exhausting routine for many (Pourghaznein, Heydari, & Manzari, 2018; Tong et al., 2010; Weissman, 1990). Parents had to take leave from work periodically to care for their child, impacting job progression and stability and even worse, parents could lose their only source of income (Cimete, 2002; Sari, Allenidekani, & Afyanti, 2018; Tong et al., 2010; Wightman et al., 2019). Parents reported feeling resentful due to their lives being dictated by their child's disease and treatment process. Their leisure or job-related activities could be interrupted at any time by unpredictable medical crises (Dracopoulos & Weatherly, 1983). Some fathers resented their jobs which limited their involvement in the care of their child (Sampson, 1975).

"My husband has been unemployed from four jobs due to frequent breaks because of our child's illness. Now he works at a strenuous low-paying job."
 ((Cimete, 2002))

Psychosocial distress

Some parents expressed guilt over their perceived role in contributing to the disease process and the complications as a result of their mistakes and carelessness (Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Sari et al., 2018; Wightman et al., 2019).

"Yeah, I feel guilty, yeah, I don't. If the doctor gets mad at me, I don't mind, I accept that. Indeed, I am wrong."
 ((Sari et al., 2018))

They had little to no time for their own goals and aspirations, having to forsake a social life outside of their family, leisure, job advancements, education or the opportunity to find a romantic partner (Dracopoulos & Weatherly, 1983; Geense et al., 2017; Mieto & Bouso, 2014; Pourghaznein, Heydari, & Manzari, 2018; Sari et al., 2018; Tong et al., 2010; Wightman et al., 2019). Parents reported ending up stifling their own aspirations and feelings, resigning to their circumstances (Pourghaznein, Heydari, & Manzari, 2018).

"I have accepted that all the good things are over for me, so I do not have any wishes for myself anymore."
 ((Pourghaznein, Heydari, & Manzari, 2018))

Family structure

Inability to care for other children

Hemodialysis requires frequent trips to dialysis centres and attentive care from the parents which reduces parents' time for other family

commitments (Pourghaznein, Heydari, & Manzari, 2018; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Sari et al., 2018; Tong et al., 2010). Parents also expressed that the inability to care for their other children was a source of stress, being unsure of how this situation would impact their children (Cimete, 2002). They were concerned that the significant time and energy spent on the child with CKD would cause envy and bitterness in the siblings (Cimete, 2002; Dracopoulos & Weatherly, 1983; Tong et al., 2010; Wightman et al., 2019).

"I had to abandon my youngest daughter and really in hindsight, that was hard for me, to abandon my other girls, my other children, but you have to. I had to explain that I needed to focus on (my son), he needs me, he needs to get well."
 ((Tong et al., 2010))

Strain on marriage

Most parents explained that the child's kidney disease had placed a huge strain on their marriage, due to unmet expectations and the lack of time available for each other (Cimete, 2002; Dracopoulos & Weatherly, 1983; Nicholas, 1999; Pourghaznein, Heydari, & Manzari, 2018). This resulted in frequent arguments, especially when the diagnosis was first known, and resulted in the possibility of divorce (Cimete, 2002; Dracopoulos & Weatherly, 1983; Nicholas, 1999; Pourghaznein, Heydari, & Manzari, 2018).

"I got depression, I'm taking medicine for a year, my husband is both nervous and bored. My relationship is very cold."
 ((Pourghaznein, Heydari, & Manzari, 2018))

Tensions within family

The increased tensions within the family led to increased family conflicts, especially due to the reluctance to talk with one another and impaired ability to make decisions and resolve conflicts (Sampson, 1975). Mothers were often the main caregivers for these patients and sometimes they felt overwhelmed by the big responsibility on their shoulders (Cimete, 2002).

Lack of resources

Formal support

The chronicity of the illness and the nature of dialysis greatly hindered the education of children with CKD. This was a major source of sorrow for parents, especially if educators and schools were not supportive of their children's needs (Cimete, 2002; Dracopoulos & Weatherly, 1983). Parents were unhappy and exasperated if medical staff acted in a hostile and careless manner towards them, especially nurses who did not truly understand their predicament, their child's needs, and did not provide an adequate standard of care for their child (Nicholas, 1999; Tong et al., 2010; Weissman, 1990). Some parents felt that they were not part of the decision-making process and not actively involved in the management and care of their child (Tong et al., 2010). Their feelings and concerns were not taken into account and little attention was given to these parents (Pourghaznein, Heydari, & Manzari, 2018; Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018).

"If you ask them more than two questions, you're a problem parent."
 ((Tong et al., 2010))

Parents, having to deal with bureaucracy and the never-ending list of tests, prescriptions and appointments, sometimes felt that they were alone in the fight for their child's health (Cimete, 2002; Tong et al., 2010).

"You go to the hospital and you're a soldier for your child, you're there mainly for him, you're there for him, not for yourself... Sometimes they make it so difficult for you and it's like I feel like you're in a battle, and you're battling for your child."
 ((Tong et al., 2010))

Financial burden of the disease included more than just procedures and medications. The cost of travel, dietary restrictions, and other household expenses all added on to the constant strain on family finances (Cimete, 2002; Dracopoulos & Weatherly, 1983; Pourghaznein, Heydari, & Manzari, 2018; Sari et al., 2018; Tong et al., 2010; Wightman et al., 2019). While some parents received help from their families, the assistance was often not guaranteed and they were unsure when it would end (Cimete, 2002). They often had to cope with the steep insurance co-pay ratios (the ratio of claim amount in an insurance policy to be borne by the insured out of pocket) and the uncertainty that insurance companies would restrict or stop coverage (Cimete, 2002; Wightman et al., 2019).

"Sometimes I do not know what to make for my son. The doctor has advised me to feed him food like fish to make him strong, but I cannot. I cannot afford it. What can I do?"
 ((Pourghaznein, Heydari, & Manzari, 2018))

Informal support

Parents stated that they sometimes felt distant from their family and friends, whom they felt did not comprehend their situation (Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018; Sampson, 1975). Due to the constant care parents had to provide, they often felt detached from the outside world (Middleton, 1996; Wightman et al., 2019). It was also difficult to find others, including medical staff, who could truly understand their situation and empathise with them (Middleton, 1996; Wightman et al., 2019).

"It is so hard; no one does understand your conditions, even your husband. They blame mothers, even when children eat something that is not good for them."
 ((Pourghaznein, Heydari, Manzari, & ValizadehZare, 2018))

Unprepared for change

The loss of normality in the child's life brought about anguish, resentment and apprehension in their families (Dracopoulos & Weatherly, 1983; Wightman et al., 2019). Children with CKD often went through various emotional and behavioural changes such as hostility and depression, and parents found themselves ill-equipped to handle this due to limited knowledge and available assistance (Sari et al., 2018; Tong et al., 2010).

"Usually, my boy will play with his bicycle somewhere. But now, he is just silent and passive..."
 ((Sari et al., 2018))

Unrealistic social expectations

Stigmatisation of caregivers

Parents wrestled with various social stigma and expectations, dealing with judgment from outsiders, other parents and medical staff (Wightman et al., 2019). This source of distress was especially pertinent for families already dealing with other forms of societal stigmatisation such as being part of a minority group or families that had to depend on others for financial aid (Wightman et al., 2019). Parents also faced societal pressures to earn an income despite having to provide care for their chronically ill child (Wightman et al., 2019).

"Everybody says, 'So why can't you work?' What do you mean, why can't I work? I still have to care for my baby. I still have to make sure he's here..." (Wightman et al., 2019)

Discrimination of child
Parents reported that seeing their children being stigmatised pained them greatly (Wightman et al., 2019).

"A lot of people would point at him because he was chubby, and people will say at the store, 'Oh, look at him. He's so big,' or 'He's so chubby,' and 'Look at his cheeks.' At first I didn't pay attention to that, but with the time it started bothering, like, 'Mind your own business. Why are you asking me?'" (Wightman et al., 2019)

Discussion

We identified various sources of distress affecting parents of children with CKD undergoing dialysis. Hopelessness and despair prevailed in various areas from the moment diagnosis was revealed, coping with treatment and the long road ahead. Parents reported being depressed, socially isolated and misunderstood, dealing alone with family struggles without adequate formal and informal support.

Our results are consistent with the review by Tong et al. (2008), which had laid out similar themes including psychosocial impact of child's illness, interpersonal issues as well as external concerns. Our results, however, included new themes such as the unrealistic social expectations caregivers face and their unpreparedness for change. Our new findings may likely be due to the inclusion of studies published after Tong et al. (2008) that provided new insights to challenges caregivers face. The continued presence of similar sources of distress more than a decade later reflects a possible lack of progress in the support systems for caregivers and their families and signals the need for more work to provide these families with the relevant assistance required.

Extensive literature on the caregiver burden of children with chronic illnesses reported similar findings (Coughlin & Sethares, 2017; Cousino & Hazen, 2013; Nabors et al., 2013; Pinquart, 2018). A recent review (Smith, Cheater, & Bekker, 2015) reported difficulties of physical and emotional burdens, lack of support, adaptation to evolving role and financial woes.

Cognizant of the fact that the technology and standard of care for children with CKD has advanced significantly in the past two decades, we have still included studies published prior to 2000 because the psychosocial impact and distresses experienced by parents caring for children on dialysis reported by these older studies are still relevant, and echoed by recent studies included in our review.

The chronicity of the illness and the high level of care necessary for these children with CKD, on top of external stressors like societal stigma, may have detrimental effects on the psychological and physical health of caregivers, which in turn affects the quality of care they can provide for their child. Parents of children with developmental disorders and mental health problems reported poorer self-rated health and greater number of chronic conditions as a result of the chronic stress of caregiving and the stigma they faced (Song, Mailick, & Greenberg, 2018). A meta-analysis described how parents of children with chronic health conditions are more likely to develop depressive symptoms than their counterparts (Pinquart, 2019).

The question to ponder upon would be: should healthcare workers accept parental distress as an inevitable part of the disease process, or should efforts be undertaken to help alleviate distress and restore hope? We postulate several sources of distress that could be alleviated. Actionable areas can be found in the healthcare system and healthcare workers. Nurses and doctors need to take extra care to be more empathetic, and incorporate family-centred care practices (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). Key tenets of Family-Centred Care (FCC) include acknowledging the

family as the child's primary source of strength and support, placing importance on the child's and family's perspectives in clinical decision-making and enhancing parent's confidence in their roles through positive health care experiences. This is illustrated by the positive experiences of families and staff during implementation of Family-Centred Care in a 15-bed Heart and Kidney Unit (Titone, Cross, Sileo, & Martin, 2004). Hanson and colleagues (Hanson, Craig, & Tong, 2017) have also emphasised patient and family-centered care as a distinctive feature of high-quality pediatric care, and 'central to caring for children with chronic kidney disease'. Various aspects of bureaucracy can be simplified so that parents feel they have a partner advocate for their child instead of battling for their child alone.

Parent-to-parent support group is an avenue for parents to engage with other parents who could understand their situation and reverse their sense of social isolation. With peer support programme, parents of special needs children showed increased confidence and problem solving capacity (Ainbinder et al., 1998; Singer et al., 1999), and mother's mental health status improved (Ireys, Chernoff, DeVet, & Kim, 2001). Peer support is offered routinely as part of renal care to per NICE guidelines. However, not all renal units have the resources to train peer supporters and implement a peer support program.

Religiosity and spirituality can be considered as an avenue for psychological respite for caregivers. An integrative review on the role of religious/spiritual beliefs help in restoring hope, in coping with illness, giving a better quality of life and minimizing depression (Bravin, Trettene, Andrade, & Popim, 2019). Moreover, the religious community can provide a source of social support for families. Conducting more studies to evaluate positive factors (resilience, coping mechanism) in families that thrive and cope despite managing a child with CKD, will provide more answers on how to reduce parental distress (Cimete, 2002; Paula, Nascimento, & Rocha, 2008; Tong et al., 2010).

Practice implications

Healthcare professionals taking care of pediatric patients with CKD should screen parents early for parenting stress and direct these affected parents towards relevant resources to receive necessary psychosocial and community services to better cope with care for their chronically ill child and to preserve the integrity family dynamics.

Limitations

Our study has several limitations. Despite our efforts to consolidate the independent searches, some studies may have been omitted due to unclear titles and abstracts and poor indexing. Only literatures published in English or with English translation were included. Most included studies were conducted in Western countries hence applicability to other countries may be limited, due to differences in accessibility to health care, insurance and social/financial resources. Nonetheless, results from the few included studies from non-Western countries show similar sources of parental distress with studies from Western countries. This shows that many stressors are universal, although the extent experienced by parents may differ according to the healthcare and cultural context, as well as the support systems available. Lastly, we included all the studies that had shared any sources of distress such as psychological, physical, and financial hardship of caring for pediatric CKD patients which may have missed pertinent details regarding specific types of distress. The future studies could consider exploring each of these stressors in details both quantitatively and qualitatively to provide individualized support to the needy parents.

Conclusion

Parents of children with CKD face many sources of distress during the caregiving process, from difficulty in acceptance of the diagnosis

to dealing with judgment and stigmatisation from family and acquaintances. Some sources of distress may be mitigated by taking specific actions. These actions can be simple acts of kindness, empathy and creating trust initiated by the healthcare team and implementing family-centred care approaches in the pediatric renal unit, which includes peer parent support.

CRedit authorship contribution statement

Zhi Hao Ong: Conceptualization, Methodology, Investigation, Writing - original draft. **Cheng Han Ng:** Conceptualization, Methodology, Investigation, Writing - original draft. **Pei Lok To:** Conceptualization, Methodology, Writing - review & editing. **Megan Jia Xuan Kiew:** Investigation, Writing - original draft. **Yi Huso:** Methodology, Writing - review & editing. **Shafaly Shorey:** Methodology, Writing - review & editing. **Yvonne Peng Mei Ng:** Conceptualization, Methodology, Writing - review & editing.

Declaration of Competing Interest

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2020.10.018>.

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