


Examining the Roles and Experiences of Fathers of Children With Chronic Kidney Disease

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Abstract

This study examined roles and experiences of fathers of children with chronic kidney disease (CKD). Based on interpretive description, semistructured interviews were conducted with 22 fathers of children receiving a range of treatments (transplant, peritoneal dialysis, hemodialysis, and CKD not requiring renal replacement therapy). Fathers described various experiences and means of adjusting to shifts associated with pediatric CKD. These included loss of personal control, a sense of personal isolation, and a stance of remaining strong amidst personal suffering. Nuanced differences according to modality of CKD care were identified. Fathers engaged in strategies that fostered coping, such as remaining positive and taking charge. They conveyed deep love for their child, and demonstrated ingenuity and persistence in care. Few resources of support were accessed by fathers. Study recommendations invite holistic approaches to health care, with improved resources for families—including fathers—in addressing the needs of this population.

Keywords

interpretive description, families, fathers, fathering, illness and disease, chronic, interviews, semistructured, lived experience, nephrology, transplantation

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Introduction

The experiences of fathers and how they support their child with chronic kidney disease (CKD) is underrepresented in the literature (Gannoni & Shute, 2010; Swallow, Macfadyen, Santacroce, & Lambert, 2012). Mothers are typically seen as the primary caregiver to their child with CKD (Aldridge, 2008; Nicholas, 1999), and the literature tends to focus on mothers' experiences as opposed to those of fathers (Aldridge, 2008). Of note, some articles that focus on "parents" variably exclude or lack specificity about fathers (Aldridge, 2008; De Paula, Nascimento, & Rocha, 2008; Gannoni & Shute, 2010; Nightingale, Sinha, & Swallow, 2014; Swallow, 2008; Tong, Lowe, Sainsbury, & Craig, 2010). Given a gap in knowledge about fathers' experiences in CKD, the broader fatherhood literature was accessed relative to chronic conditions (Higham & Davies, 2013; McNeill et al., 2014; Nicholas et al., 2009; Swallow, Lambert, Santacroce, & Macfadyen, 2011). Relevant studies tend to reflect qualitative methods (Swallow, Allen, et al., 2012).

Overall, the literature identifies fathers as a "protector" and "provider" within the context of the family (Higham & Davies, 2013; McNeill et al., 2014; Swallow et al., 2011; Swallow, Allen, et al., 2012). They are reported to assume

these roles amidst worries and challenging factors affecting their family such as long-term care needs of the child and family (Swallow et al., 2011), financial concerns related to family needs (Nicholas et al., 2009), and a perceived need to remain strong and convey support for the family (Higham & Davies, 2013). In some instances, fathers are described to be impeded in their sought after roles. For instance, barriers exist relative to caregiving because of employment inflexibility, emotional strain, and personal exhaustion (Nicholas et al., 2009). Fatherhood roles include direct care for the child, supporting/holding the child when she or he receives difficult treatments (e.g., medicine, needles, cream applications; Swallow et al., 2011), and seeking to ensure the child's comfort (Tong et al., 2010). Fathers generally provide more care in the evening because they often are less available during the day due to out-of-home employment (McNeill et al., 2014).

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Research is needed in clarifying parental care roles for children with CKD (Swallow, 2008). Lamb (2010) notes a shift in the way paternal roles have been viewed over time, moving from predominantly a breadwinning role to that of greater involvement in a child's life. Lamb (2010) notes that fathers hold multilayered roles: "companions, care providers, spouses, protectors, models, moral guides, teachers, and breadwinners—whose relative importance varies across historical epochs and subcultural groups" (p. 3).

Fathers of children with chronic health conditions reportedly experience substantial emotional burden (Higham & Davies, 2013; Swallow, Macfadyen, et al., 2012), which is exacerbated by being "left out" in terms of emotional support and discussion regarding the ill child's health care (Gannoni & Shute, 2010). Parental strain includes sadness in observing the child suffer, personal exhaustion, anger, and extended hours away from home due to employment demands (Nicholas, 1998).

Mothers reportedly perceive their husband/male partner to be substantially affected by their child's CKD and the changes that this condition brings to family life (Nicholas, 1998, 1999). Nicholas (1998) reports cases in which CKD is thought to have introduced or exacerbated marital strain. In other cases, the marital relationship is perceived to be nurtured by the presence of CKD in the family, particularly if parents work together to address the needs and challenges.

In their evaluation of caregiving mothers and fathers, Fedewa and Oberst (1996) note that family caregivers who also work outside the home experience greater levels of parental stress. Findings generally place mothers and fathers at emotional and adaptational risk (Cousino & Hazen, 2013); however, much less is known about fathers than mothers in pediatric CKD. Greater understanding about fatherhood in CKD—from the perspective of the fathers themselves—is needed to advance family-centered practice and CKD program planning. To that end, the following research questions were addressed via first-person accounts from fathers:

Research Question 1: What roles do fathers play in pediatric CKD care?

Research Question 2: What is the lived experience of fathers of children with CKD?

Method

Because little is yet known about how fathers experience pediatric CKD, a priority of this study was to identify and explore these realities from the perceptions of fathers. This invited an open exploratory research design (Creswell, 1998; Gubrium, 1988; Lincoln & Guba, 1985; Meucke, 1994; Tesch, 1990), drawn from an interpretive description approach (Thorne, 2016). Interpretive description offers "smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and

generating an interpretive description capable of informing clinical understanding" (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 5). This approach seems ideal in eliciting on-the-ground experiences and recommendations for clinical practice. Hunt (2009) notes that the clinically grounded focus of interpretive description "orients data analysis toward the development of findings that will assist healthcare professionals in their practice" (p. 1289). Thorne et al. (2004) further posit that interpretive description yields "a coherent conceptual description that taps thematic patterns and commonalities believed to characterise the phenomenon that is being studied and also accounts for the inevitable variations within them" (Thorne et al., 2004, p. 7). Accordingly, this approach is well suited to the aims of greater clinical understanding relative to the understudied experiences of fathers of children with CKD.

A purposive sample was sought, consisting of fathers of a child with CKD who participated in a single semistructured interview. The sample was drawn from a large CKD program in a tertiary-level pediatric hospital located in a large, culturally diverse city in central Canada. Participants were stratified to include the following treatment modalities as a means of exploring experiences across varying CKD care trajectories: CKD not requiring renal replacement, hemodialysis, peritoneal dialysis (PD), and transplantation.

Potential participants were initially informed about the study by a known health care provider. Each father was then contacted by telephone to explain in greater detail the purpose and procedures of the study, and to inquire about potential interest in study participation. All participants consented to participation through an informed consent process, including signed consent forms.

Interviews were conducted based on McCracken's (1988) long interview method. Guided by an interview schedule outlining broad, open-ended questions, an experienced qualitative research interviewer (trained and supervised by the author who brings extensive qualitative research experience) invited substantial breadth of perspective yet focus on interview questions and probes. All interviews were completed prior to the commencement of data analysis, and lasted approximately 1 hour. Interview questions addressed the roles and experiences of fathers, and perceived impacts of CKD. At the conclusion of each interview, participant demographic data were elicited, such as family constellation, age, socioeconomic status, leisure activities, and employment detail.

Interviews were audio recorded and transcribed verbatim. Transcripts were subjected to coding, concept saturation, and theme generation, assisted by qualitative data analysis computer software (N-Vivo). Line-by-line coding within transcripts and then axial coding across transcripts identified poignant findings from the data. This was completed by two reviewers who independently coded the data and discussed emergent codes. Consensus related to themes followed from this process.

Trustworthiness of emerging themes (rigor) was verified through thick description (substantial description about sample characteristics), referential adequacy (reference to interview quotes to demonstrate emerging themes), negative case analysis (search for instances in the data of contradictory findings), and peer debriefing (pediatric CKD health care providers invited to consider the feasibility and relevance of themes; Lincoln & Guba, 1985). Data saturation was achieved. Ethical review and approval were obtained from the host institution. Care was taken to code data in ways that maintained participant anonymity, and the data were stored in a secured location. Careful adherence to ethical standards and protocol, as approved by the Research Ethics Board, was incorporated throughout the study.

Results

A total of 22 fathers of children with CKD were interviewed. Fathers were selected according to diversity of treatment modalities received by their child including transplant ($n = 8$), hemodialysis ($n = 5$), PD ($n = 4$), and chronic renal insufficiency (not on dialysis nor transplanted; $n = 5$). Fathers' mean age was 43.8 years ($SD = 9.54$ years). Most lived with the ill child's mother who generally was the primary caregiver (or cocaregiver) for the ill child. Family annual income ranged between CA\$27,000 and CA\$200,000 ($M = CA\$68,846$), and all but two fathers were employed. In terms of marital and family status, the majority of fathers were married and within a nuclear family unit. Most fathers had two or more children. Children with CKD were between the ages of 1 and 18 years ($M = 11.45$ years). In addition, most fathers identified themselves as Canadian, although some had immigrated to Canada from other countries. Half of the fathers reported no health problems, with others reporting the following challenges: difficulty sleeping, diabetes, hypertension, kidney disease, heart conditions, hernia, high cholesterol, and knee-related issues. Fathers identified a range of leisure activity/interests; however, many felt that they could not participate because of family caregiving needs. See sample demographic data in Table 1.

Fatherhood Roles

Fathers described many roles within their family. Several identified themselves as their child's coprimary caregiver. They also identified providing support to their partner, ill child, and other family members as common and important roles. In addition, fathers assumed unique roles related to having a child with CKD, including care management responsibilities such as administering medication, transporting the child to and from the hospital, and supporting family normalcy. Fathers were advocates for their child in navigating the health care system and seeking resources.

Fathers generally reported little time for self-care and engaged in few activities beyond employment, their child's

Table 1. Participant Demographic Information.

Fathers ($n = 22$)	
Treatment modality	
Predialysis	4
Hemodialysis	6
Peritoneal dialysis	4
Transplant	8
Father's employment	
Employed	20
Unemployed	2
Annual family income (in CA\$)	
\$20,000–\$39,999	4
\$40,000–\$59,999	2
\$60,000–\$79,999	4
\$80,000–\$99,999	1
≥\$100,000	2
Did not respond	9
Father's marital status	
Married	18
Separated	1
Divorced, remarried	1
Divorced, single	1
Did not respond	1
Number of children in family	
1 child	6
2 children	9
3 children	5
4 children	0
5 children	2
Age of child with CKD	
≤5 years	3
6–10 years	5
11–15 years	6
16–18 years	6
Did not respond	2

Note. CKD = chronic kidney disease.

health care regime, and other family responsibilities. Ensuring sufficient financial resources was of primary concern to fathers. In many cases, mothers were described to provide much of the hands-on daily care for the child; however fathers, together with mothers, sought to promote care, emotional support, and security for the family. As an example, a father stated,

As far as talking about the disease and her (the ill child's) problems, we do that on a regular basis. We are very much open as far as talking and discussion with my . . . daughter that has the illness about what she needs to do in her life in order to lead a healthy lifestyle.

Adjusting to CKD

Fathers described a range of experiences and emotions related to CKD. Immediately after diagnosis, feelings of disbelief and shock were reported, as illustrated by a father who

stated, “Well it was kind of unbelievable . . . There was no inkling of a problem so it was a surprise.” Initial experiences of upset were eventually followed by an increasing sense of normalcy, as CKD and its care were integrated into daily life: “Basically it’s normal, it’s routine, it’s normal, like we’ve accepted it.” Generally, loss and adjustment were noted along with a required reorganization of the family routine according to the child’s care needs. Having to adjust to this new routine was variably challenging for fathers, as illustrated by a father who stated,

I have changed a lot . . . I was a very, very easygoing person, very calm person. I used to have patience like no tomorrow, I used to put up with everything. It has changed my personality from night to day . . . Patience I mean I don’t have it. (Father of a child not yet on dialysis)

Another father indicated,

So one (problem) drops off, one is picked up. It’s like a schedule. It’s like a machine right now. Sometimes I sit down and think . . . We don’t have rest. We don’t have a break. We just have to “do” . . . You move. (Father of a child on PD)

Family life was reportedly reconfigured to attend to the many demands of the illness and its treatment. One father stated, “since then (diagnosis of CKD) the whole life changed because (of) . . . the health of the child . . .” Another added, “We have no control over anything or very little control over things.” Profound emotional impacts for fathers and their families were identified:

Some days you’re fine. It’s like okay, you know, we’ve got this under control and he’s going to beat it and you’re fine with it. And usually the next day is really rough where you can’t keep your emotions in check, you cry a lot and you think to yourself “why my kid?” I can handle it, but why them? They’re so young! Hey, he hasn’t had a chance to live. (Father of a child on PD)

Isolation

Fathers identified few supports outside their immediate family, and in some cases, they relied on their wife/partner for support. Fathers commonly described a stance of remaining strong and being supportive to others in the family. Yet they lived within a pervasive and tenuous struggle of managing uncertainty and worry, ongoing time pressure/shortage, and a general lack of accessible supports.

For us there is always something to do. We never sit down and let rest like. That’s the way for us . . . 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 of a child on PD)

Fathers described others as not particularly interested or appreciative of their struggles, and felt that these others

could not fully understand the difficulties of CKD without firsthand experience. Rather than seeking support, fathers appeared to largely withhold sharing about their difficulties and felt that their primary response was to demonstrate strength by not sharing negative emotions, as exemplified below.

Other than close friends . . ., (my child’s condition and treatment) is not something I would share with everybody because there is no sense . . . I can deal with the situation. (Father of a child not requiring renal replacement therapy)

Except for the immediate family if you show any kind of emotion about it, just to get it off your chest, it’s hard to do with other people. That becomes difficult. They look at you and say “I don’t want to deal with this.” So yeah, you feel isolated . . . (Father of child on hemodialysis)

It is hard to talk to other people because they don’t understand and when you tell them, you can tell the look on their face like, “oh my God.” (Child not requiring renal replacement therapy)

Generally, fathers opted to not share their personal struggle with others because of a lack of receptiveness and/or fathers’ aim of not burdening others. Several fathers remarked that this left them in a precarious position of emotional pain with few, if any, resources to address or ease that pain.

Nuanced Differences Between CKD Treatment Modalities

Although common experiences were identified, fathers also identified a range of impacts associated with CKD, with subtle differences between treatments of chronic renal insufficiency not requiring renal replacement therapy, hemodialysis, PD, and transplantation. In cases in which children did not require renal replacement therapy, fathers grappled with the possibility of future dialysis or transplantation. Yet they sought to maintain normalcy and think positively:

My main goal as far as day-to-day living his life up until transplant or even after, live as normal a life as possible as opposed to thinking about what would take place, that’s absolutely ludicrous. There are no outward signs, you can still do everything. (Father of a child not requiring renal replacement therapy)

Although these fathers appeared least encumbered with daily demands and impositions of CKD, a recent experience of receiving a diagnosis resulted in struggle for fathers, as exemplified by a participant who expressed surprise and dismay by his child’s recent diagnosis:

He (the child) is very active, he play, all the day he play and he never say, “I am tired . . .” When the doctor told me that they are going to change the need for dialysis and they need to for him

. . . I surprised . . . he is very active, he don't feel anything, even he didn't tell me he had the pain in his stomach or headache, nothing complain. (Father of a child not requiring renal replacement therapy)

Fathers of children on hemodialysis generally reported extensive worry, and described a sense of helplessness in not having an active role in daily CKD treatment:

Every now and then you'll just be sitting there doing something and then all of a sudden these horrifying thoughts of something going wrong occur for no apparent reason and that happens periodically. You're constantly worried. (Father of a child on hemodialysis)

Fathers of dialyzed children (both hemodialysis and PD) generally looked forward to kidney transplantation because they anticipated that quality of life for their child and family would improve with a transplant: "I think everything will balance out and everything will go smooth from that (transplant) onwards" (father of a child on PD).

Fathers of children receiving PD and hemodialysis described experiencing stress, with fathers of children receiving PD often describing rigorous daily difficulties and demands of PD. Relative to fathers of both nondialyzed children and children on hemodialysis, the fathers of children receiving PD more often and seemingly more intensely described daily strain imposed by the responsibilities of care:

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. I'm stressed out. My wife is stressed out. We have to work. We go to work. 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. And we are always thinking, "oh what is going to happen next, what is going to happen next?" Or is she going to cry, am I going to have to wake up again? It's kind of tough. Life is tough. (Father of a child on PD)

Fathers of a child on PD most profoundly reported little time for self-care, social interaction, or recreation: "I used to do a lot of sports before, but right now I don't have any time. I barely have any time to do anything apart from taking care of my family" (father of a child on PD). Another father stated, "We should probably go out more, but we don't. We'd rather make sure that the children are taken care of" (father of a child on PD).

The fathers of transplanted children grappled with uncertainty associated with the function of the graft, but generally conveyed themselves as less deleteriously affected in terms of intrusion on daily activities: "Ever since the transplant, (the ill child's) care has been reduced to medication in the morning, medication at night. So that's a far cry from what we had, what he needed before the transplant." Relative to others, these fathers typically had dealt with CKD for a

lengthier time. Generally, their child was older and had been unwell for a longer period of time. However, because their child had received a transplant, these fathers did not have as many duties related to the child's daily health care. In a few cases, fathers reported difficulty relinquishing their level of pretransplant care because of habitually providing such a level of care and/or worry about risk of transplant rejection:

Yeah . . . even with the drugs, she knows them, she is so bright. Whatever she has to take in the morning, she knows. I call her, I call her, say at 8:30 in the morning, I call home, I say _____, and she says, "Daddy I know, you don't have to call me." Hang up. (Father of a child with a transplant)

For the most part, fathers of transplanted children reflected that they and their families had been, "on a long road, but now things are manageable." They generally felt that their lives were returning to "normal," and tended to be positive and optimistic: "Even if it (the transplanted kidney) deteriorates, there are always other options. He can have another transplant. He can go on dialysis. The prospects don't look good but they don't look very, very bad."

Action Orientedness, Remaining Positive, and Moving Forward

Some fathers dealt with day-to-day struggles and concerns by "taking charge" or implementing an action-oriented approach, which entailed concrete management or attention to needed tasks in moving forward:

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. (Child not requiring renal replacement therapy)

Several fathers described activity as a means of distraction, the promotion of balance, and/or a means of maintaining focus in the midst of their experience of adversity and strain in their daily lives. Specific approaches integrated by participants were exercise, work, and engaging in religious or spiritual beliefs. One father conveyed his personal approach as, "praise God. Don't worry too much." Other fathers described a process of "downward comparison" in which fathers reflected on other illnesses and were grateful that their child was not more unwell or negatively affected:

What has been able to get me through . . . is to know that families are in worse situations. So that is why I don't complain because well there are others that are worse off, I see them and what they are going through, listening to the amount of stress they are under. So I consider myself blessed. . . it makes things a lot easier for me to know that it could've been much worse. So as the saying goes, I count my blessings. (Father of a child on hemodialysis)

Such cognitive formulation reportedly rendered fathers' concerns and struggles as less debilitating. Specifically, fathers juxtaposed CKD against a hypothetically worse set of circumstances. They described emotive and cognitive shifts in terms of what mattered (and conversely no longer mattered) in their lives. Their love for, commitment to, and time spent with their children and family often were conveyed as newly emerged or heightened priorities that had vicariously resulted from their child's illness. Accordingly, despite profound struggles, fathers also described positive perspectives and priorities:

It puts things in perspective for you early . . . You learn very quickly what is important in life . . . I think you also appreciate the time you spend with your kids . . . It can totally change you, it will crystallize what is important and that is more than just giving you a perspective. (Father of a child not requiring renal replacement therapy)

Our priorities are more—I think we have spent more time with our kids, than a lot of other parents, especially me. I have spent a lot of time with my kids. (Father of a child on hemodialysis)

We just have to enjoy anything that we can enjoy as it is handed to us. Every member of the family has a true sense of appreciation for, you tend to take less for granted. You appreciate health, you appreciate life overall . . . So you definitely have a totally different perspective in life, a much richer one. (Father of a child with a transplant)

Discussion

Fathers generally had an integral role in family care and experienced substantial impacts as a result of their child's CKD. Fathers, along with their partner, integrated care into daily life. Loss and adjustment were a part of their experience; yet fathers coped in relative isolation and with little support. These findings add to the literature by suggesting that the impact of CKD on fathers may be nuanced by the expression and severity of their child's condition and her or his modality of treatment. Paternal activities that counteracted strain and nurtured coping, such as exercise and spirituality, often were solitary in orientation. In some cases, employment imposed additional stress through rigidities that added pressure in care regimes.

These findings corroborate earlier literature suggesting that fathers of children with chronic illness, in this case CKD, experience emotional turmoil (Higham & Davies, 2013; Swallow, Macfadyen, et al., 2012). Their roles as caregiver, provider, and protector seem ambiguously understood and underrecognized in current practice and family support discourses. Roles of fathers seem largely assumed and underrecognized within clinical encounters, with relatively limited consideration for the personal or relational impacts or contributions fathers make to their family or the ill child's health care outcomes. This has implications relative to beliefs

about, and arrangements for, care delivery. For example, if a father desires to be a key caregiver for his ill child, he may be impeded by imposed patterned "tasks" of care and financial provision arrangements as ascribed by sex- and role-determined expectations. These elements may impose deleterious and undesired impacts both on mothers and fathers, and on how parents jointly navigate family care. If employment arrangements lack flexibility, fathers are likely to experience less support and time to engage with their child, potentially resulting in relational costs, emotional strain, and/or personal isolation. This risk is amplified from a social determinants of health perspective, whereby fathers with less job security and flexibility (along with potentially other social disadvantages) can face additional impediments in navigating care. Unfortunately, this is amplified by clinical supports and services that tend to be offered within daytime business hours (typically when fathers are at work).

Paternal roles and experiences indeed appear to be nuanced by care activities and meanings ascribed to CKD as well as other social-political and gendered considerations. The illness of their child left fathers in varying levels of loss and pain, often in the context of insufficient supports and guidance for how to navigate this emergent form of fatherhood. Although resilient in forging pathways forward and persevering in paternal care, fathers were relatively isolated, sometimes with limited resources and social capital in their adjustment journey. Additional examination is warranted in further exploring constraints and opportunities, and better understanding fatherhood and how fathers, their partners, their children, and others contribute to, and are affected by, this experience. Understanding the relational qualities, for instance, between fathers and their ill child, or fathers and the ill child's siblings, invite further inquiry in the ultimate aim of supporting family well-being. Such multidirectional and layered analyses could inform clinicians and program planners in better understanding and proactively responding to the complexity of family life relative to pediatric CKD. Educating service providers on the multilayered, varied, and sometimes competing roles that fathers manage may help to increase awareness and foster tailored approaches to fathers' inclusion in care.

Fathers emerged in these data as vulnerable, yet committed and resilient. This highlights a textured experience of fatherhood love and struggle, which in turn invites understanding and support within models of family-centered care. Accordingly, greater study of, and support to, couples (or multiple parents/cocaregivers with the family unit) merit advancement in assisting parents as they individually and collectively navigate CKD care. Fathers' experiences are both similar to, and different from, those of mothers. In an earlier study, mothers' experience of CKD was marked by extraordinary levels of care. Unlike mothers, fathers' discourse was less associated with the "work" of care. Also, resources and support from health care providers seemed to be more available and targeted to mothers. This invites a

potentially broader range of educational opportunities and supports for fathers of children with CKD. Recommendations of targeted support for fathers include peer connection with other fathers facing a similar journey. Educational and support topics that may be valued need to address the concerns and sensitivities of fathers. Examples consist of resources that encourage ways to father a child with a chronic condition, actions that could make life better for children with CKD and their family, and means to integrate and navigate work demands with paternal care. Engaging fathers in community and family tasks that advance understanding and coping may support adjustment and proactive strategy development.

Study Limitations

This sample was drawn from a single tertiary-level pediatric hospital in Canada, and lacked extensive diversity relative to cultural background and parenting arrangement (e.g., sole custody caregiving fathers, same sex fathers, foster fathers). In contemporary society, the traditional “nuclear” family is shifting, and further study that addresses nontraditional families such as varying caregiver configurations is increasingly warranted. Further research is needed that can measure the extent and impact of CKD relative to the variables identified in this inquiry.

Conclusion

This study highlights fathers of children with CKD as an underserved clinical population at emotional risk. Targeted resources that address fathers’ psychosocial and adjustment needs warrant greater attention in interventional research and models of health care delivery. This invites scholarship and services that amplify and reflect fathers’ unique experiences and needs, in the aim of ultimately advancing family-centered care.

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