

# Caregiver Experience in Pediatric Dialysis

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abstract

**BACKGROUND AND OBJECTIVES:** Pediatric dialysis is thought to be burdensome on caregivers given their need to assume dual responsibilities of parental and medical management of their child's chronic illness. In this study, we seek to describe the experience of parental caregivers of children receiving chronic dialysis for end-stage kidney disease.

**METHODS:** We performed semistructured interviews of primary caregivers of children with end-stage kidney disease receiving chronic peritoneal dialysis or hemodialysis for at least 8 weeks from March 2016 to April 2017 at 3 pediatric dialysis centers in the United States. We performed a thematic analysis to inductively derive and identify themes and subthemes related to positive and negative caregiver experiences.

**RESULTS:** Thirty-five caregivers completed interviews. Four major themes were identified, each with several subthemes: (1) caregiver medicalization (subthemes: diagnosis and initiation, disease management, and the future), (2) emotional adjustment (initial and/or acute phase, acceptance, personal growth, and medical stress and psychological burden), (3) pragmatic adaptation (disruption, adaptation of life goals and/or sense of self, and financial impact), and (4) social adjustment (relationship opportunity, relationship risk, advocacy, family functioning, and intimate relationships). These themes and subthemes reflected a broad range of experiences from positive to severely burdensome.

**CONCLUSIONS:** Caregivers of patients on dialysis report a broad range of positive and burdensome experiences. These results reveal a need for continued advocacy to support families with a child on dialysis and can be used to develop targeted measures to study and improve caregiver experience in this population.



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Dr Wightman conceived the study, developed the interview tool, administered the interviews, conceived the analysis, performed the analysis, drafted the initial manuscript, reviewed and revised the manuscript, and takes responsibility that this study has been reported honestly, accurately, and transparently, that no important aspects of the study have been omitted, and that any discrepancies from the study as planned have been explained; Dr Zimmerman contributed to the development of the survey tool, administered the interviews, contributed to development of the analysis, contributed to performance of the analysis, and reviewed and revised the manuscript; Dr Neul contributed to the development of the interview tool, development of the analysis, performance of the analysis, and reviewed and revised the manuscript; Ms Lepere administered the interview tool, administered the interviews, performed the analysis, and reviewed and revised the manuscript; Dr Cedars contributed to the development of the interview tool, administered the interviews, and reviewed and revised the manuscript; (Continued)

**WHAT'S KNOWN ON THIS SUBJECT:** Pediatric dialysis is thought to be extremely burdensome for both the pediatric patient and family, and these burdens are factored into recommendations about initiating, withholding, or withdrawing dialysis; however, empirical characterization of caregiver experience is limited.

**WHAT THIS STUDY ADDS:** Caregivers of patients on dialysis report a broad range of positive and burdensome experiences, including extraordinary burdens, but also acceptance and opportunities for psychological growth. These findings may lead to development of targeted measures to study and improve caregiver experience.

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Advances in medical therapies, technology, nursing, nutrition, and recognition and treatment of pain in the last 40 years have led to dramatic improvements in the expected outcomes of pediatric, particularly neonatal, dialysis.<sup>1-3</sup> When a transplant is unavailable, dialysis remains the treatment of choice for children with end-stage kidney disease (ESKD). However, although dialysis is lifesaving, it is considered to be a burdensome treatment of both the pediatric patient and family, and these burdens are factored into recommendations about initiating, withholding, or withdrawing dialysis.<sup>4-11</sup>

Empirical evidence used to quantify and characterize caregiver burden or experience is nonetheless limited.<sup>12,13</sup> In their results, authors of previous studies largely report on the negative experiences of caring for a child with chronic kidney disease (CKD), finding that parents of children on dialysis may have higher levels of anxiety affected by large family size,<sup>14,15</sup> higher rates of depression,<sup>16</sup> poorer health-related quality of life,<sup>17</sup> less time for healthy siblings,<sup>18,19</sup> greater marital strain,<sup>14,20-22</sup> and higher levels of financial stress.<sup>18,19,21,23-25</sup> Although informative, these studies have important limitations, such as small sample size (as few as 2-4 patients total<sup>14,18,19</sup>); conflicting results (eg, some studies do not reveal higher levels of parental anxiety,<sup>24</sup> mental illness,<sup>15,18,23</sup> or divorce<sup>21</sup>); reliance on earlier generations of dialysis technology, medical treatments, and nutrition<sup>15,18,20,23,26,27</sup>; and being conducted in settings with universal health care systems<sup>15-17,21-26</sup> that may not translate to the American health care system.

We sought to address some of these gaps by examining the priorities, perspectives, and experiences of caregivers of children on chronic dialysis at 3 pediatric dialysis centers in the United States. We hypothesized

that caregivers would report a wide range of experiences, characterized as significant burdens and positive influences attributed to caring for a child on chronic dialysis.

## METHODS

### Participant Selection

Participants were eligible if they were >18 years of age and were English- or Spanish-speaking primary caregivers of a child (age 0-18 years) with ESKD receiving chronic peritoneal dialysis (PD) or hemodialysis for at least 8 weeks from March 2016 to April 2017. Participants were recruited through the regional dialysis programs at Seattle Children's Hospital (SCH), Texas Children's Hospital (TCH), and the Children's Hospital of Wisconsin (CHW) through use of flyers posted in the dialysis units and clinics and through in-person recruitment by dialysis center social workers. These centers provide dialysis treatment to children living in >30% of the geographic area of the United States. Purposive sampling was used for in-person recruitment to attempt to obtain a variety of children's dialysis modality and vintage and of caregivers from minority ethnic groups. Participants were informed that investigators were interested in learning more about the experience of caregivers of children with ESKD, and, if interested, they consented to participate. No caregivers declined to participate in the study or, once enrolled, failed to complete the study.

This study was approved by the institutional review boards at SCH, TCH, and CHW.

### Data Collection

We used an iterative process to develop a semistructured interview script to use during in-person interviews with caregivers. This process began with a review of the published literature on caregiver experience in CKD followed by the

writing of an initial script that included previously described themes as well as de novo domains based on the clinical experience of the investigators related to adaptation, resilience, and financial burdens.<sup>12-14,16,18-24,26</sup> Second, 3 national experts in pediatric dialysis and 2 national experts in qualitative research methods reviewed the initial script for content and its ability to identify caregiver experience. Finally, the script was piloted with 4 caregivers of pediatric patients on dialysis in Madison, Wisconsin. After each step, improvements and refinements to the script were made. The final script is provided in the Supplemental Information.

Interviews took place in the hemodialysis unit, PD clinic, or by telephone depending on caregiver preference and lasted on average 70 minutes. Participants received a \$25 Amazon gift card after completion of the study. Interviews were performed by a male pediatric nephrologist who did not have direct medical supervision of the caregiver's child (A.W.), 2 female psychologists affiliated with the dialysis center (C.T.Z. and K.C.), and 2 female research assistants with no previous contact with the caregiver (K.L. and M. Clementi, PhD). All interviews were digitally audio-recorded and transcribed verbatim. Field notes on context were recorded immediately after each interview. Interviews of Spanish-speaking caregivers were conducted by using a certified medical interpreter, with the English interpretations transcribed. Recruitment ceased when data saturation was observed in the concurrent data analysis.

### Analysis

We analyzed the transcripts using a thematic analysis to inductively derive and identify concepts and themes of caregiver experience with an iterative and consensus approach. First, the transcripts were

independently coded by 4 investigators (A.W., C.T.Z., K.L., and S.N.) to bring multiple perspectives into the analysis and to refine the coding structure. The computer software NVivo 11 was used to assist with storage, coding, and searching of data. After coding each set of 5 transcripts, all coders met to review differing perspectives and refine code definitions. Second, after this discussion, the 4 code sheets for each transcript were distilled into a single code sheet for each transcript by 1 investigator (A.W.) and discussed with an investigator not involved in the coding to help further refine it (D.O.). Third, definitions of each code were refined by 2 of the investigators (C.T.Z., K.L., or S.N., and A.W.) and then reviewed with the group to ascertain agreement. Fourth, these codes were then used to inductively develop themes and develop a thematic schema of caregiver experience. Finally, 2 investigators (A.W. and D.O.) discussed the relationships of the final themes to refine the thematic schema of caregiver experience. A summary of our preliminary findings was shared with participants in November 2017 to inquire whether their priorities were faithfully interpreted, to enhance the developing analytical framework, and to ascertain whether the account made sense to participants with different perspectives. A certified medical interpreter was used for Spanish-speaking participants. The participants commented that the summary was informative and reflected their experiences.

## RESULTS

We enrolled 35 caregiver-child dyads with characteristics described in Tables 1 and 2. We identified 4 major themes: caregiver medicalization, emotional adjustment, pragmatic adaptation, and social adjustment. Each theme had several subthemes and are described below, with

illustrative quotations provided in Tables 3 through 6. A thematic schema revealing key relationships between these themes and subthemes is displayed in Fig 1.

### Caregiver Medicalization

At the time of their child's ESKD diagnosis and initiation of dialysis treatment, caregivers reported undergoing intensive training as de facto medical providers. They described needing to master a new medical language, technical skills, and complex daily routines for long-term disease management while simultaneously managing concerns about their child's health instability and prognosis and opportunity and risks of transplant and maintaining their customary role as caregiver to their child.

### Diagnosis and Initiation

The diagnosis of ESKD and the need to start dialysis was described as a shock by caregivers whether anticipated or unexpected (Table 3, quote 1). Caregivers described the period of dialysis initiation as a major inflection point that expanded their role of traditional caregiver to include medical provider. Learning a complex medical language, procedural skills, and judicious medical decision-making resulted in information overload (Table 3, quote 2). They recounted struggling to find information independently and only finding misleading, incorrect, or overly negative information on the Internet (Table 3, quote 3). Caregivers appreciated medical providers who took the time to explain things and were direct and concrete (Table 3, quote 4).

Caregivers felt there was not a decision to be made about initiating dialysis (Table 3, quote 5). They did not report seriously considering palliative or comfort care (even if they recognized that the medical providers did), only treatment options. Looking back, caregivers noted that the experience of caring

for a child with ESKD was harder than they expected at the time of initiation (Table 3, quote 6).

The initiation of dialysis forced caregivers to rebalance the needs of their child and their family when making decisions about their child's treatments. In particular, those who chose PD reported taking a more active role in decision-making than caregivers of a child receiving hemodialysis, especially because PD can be done at home (Table 3, quote 7).

### Disease Management

Caring for a child on dialysis placed unrelenting, myriad responsibilities on caregivers. They assumed responsibility for their child's medical management and any complication occurring outside of the hospital, serving as an enforcer of medical limitations on diet, fluids, medications, dialysis, and activities (eg, swimming) 24 hours a day while still maintaining their parenting role (Table 3, quote 8). They reported needing to develop competency to handle the routine tasks while always being aware of the inherent instability of a child on dialysis. The extent of these requirements left many caregivers feeling drained (Table 3, quote 9).

### The Future

Caregivers described a range of conceptions of the future. Some caregivers reported being so locked into the required daily treatments that they had little concept of the future beyond receiving a transplant (Table 3, quote 10). Others worried about the many unknowns regarding their child's future, including the unpredictable nature of disease-related morbidity and eventual mortality, to the point of overshadowing all other aspects of their child's future (Table 3, quotes 11 and 12). Caregivers of adolescents expressed anxiety over their child taking greater control managing their medications and treatment course,

**TABLE 1** Participant Characteristics (*n* = 35)

Characteristics	SCH ( <i>n</i> = 17)	TCH ( <i>n</i> = 14)	CHW ( <i>n</i> = 4)	Total ( <i>N</i> = 35)
Caregiver sex, <i>n</i> (%)				
Female	16 (94)	12 (79)	4 (100)	32 (89)
Male	1 (6)	3 (21)	0	4 (11)
Caregiver cultural background, <i>n</i> (%)				
White	13 (76)	7 (50)	1 (25)	21 (60)
Hispanic	3 (16)	3 (21)	0	6 (17)
African American	0	4 (29)	3 (75)	7 (20)
American Indian	1 (8)	0	0	1 (3)
Caregiver interview language, <i>n</i> (%)				
English	14 (82)	14 (100)	4 (100)	32 (92)
Spanish	3 (18)	0	0	3 (8)
Interview participant, <i>n</i> (%)				
Father only	1 (6)	2 (14)	0	3 (8)
Mother only	15 (88)	11 (81)	3 (75)	29 (83)
Both parents	0	1 (7)	0	1 (3)
Grandparent	1 (6)	0	1 (25)	2 (6)
Caregiver currently married, <i>n</i> (%)				
Yes	12 (70)	7 (50)	3 (75)	22 (63)
No	5 (30)	7 (50)	1 (25)	13 (37)
Caregiver employed, <i>n</i> (%)				
Yes	3 (18)	2 (14)	2 (50)	7 (20)
No	14 (82)	12 (86)	2 (50)	28 (80)
Caregiver highest level of education, <i>n</i> (%)				
High school or less	10 (59)	5 (36)	3 (75)	18 (51)
Some college	7 (41)	9 (64)	0	16 (46)
Graduate school	0	0	1 (25)	1 (3)
Other children in home, <i>n</i> (%)				
Yes	12 (70)	8 (57)	4 (100)	24 (69)
No	5 (30)	6 (43)	0	11 (31)
Distance from dialysis unit, miles, <i>n</i> (%)				
<30	6 (35)	10 (71)	2 (50)	18 (51)
≥30	11 (65)	4 (29)	2 (50)	17 (49)
Interview setting, <i>n</i> (%)				
Dialysis unit or clinic	12 (71)	14 (100)	4 (100)	30 (86)
Telephone	5 (29)	0	0	5 (14)

fear of the adult dialysis unit, and the possibility of losing insurance coverage in the future (Table 3, quote 13). Caregivers hoped for an initial or second kidney transplant and described transplant as an opportunity for the child, caregiver, and their family to regain their previous life, resume life, or begin an improved life (Table 3, Quote 14).

### Emotional Adjustment

Caregivers reported a range of emotional reactions while adjusting to their child's diagnosis and need for lifelong intensive treatment, resulting in significant psychological burdens yet also affording them the opportunity for personal growth.

### Initial and/or Acute Phase

Caregivers recounted grieving over the loss of what they could or should have been as a caregiver, one's personal and family life, and the child's typical life (Table 4, quote 1). They described feeling guilty over enforcing medical limitations, making mistakes that resulted in complications for their child, possibly playing a role in causing kidney disease, being unable to cure ESKD, and witnessing their child endure dialysis and painful medical procedures (Table 4, quote 2).

### Acceptance

Caregivers found themselves in the onerous situation of needing to accept life with a child on dialysis.

This became a challenging and highly personal process of accepting the ESKD diagnosis, the necessity of dialysis treatment, and the resulting demands and limitations placed on their lives and their families' lives. Caregivers described a range of ways in which they accepted their new situation. A few caregivers reported rapid acceptance; however, the remainder described it occurring slowly on a continuum over time, if ever (Table 4, quote 3). During this process, caregivers acknowledged their own limited ability to exert control over what would occur for their child medically and accepted that bad things could happen despite their best efforts (Table 4, quote 4). They became able to reconcile and view their situation in a more

**TABLE 2** Characteristics of Children of Participating Caregivers

Characteristics	SCH ( <i>n</i> = 17)	TCH ( <i>n</i> = 14)	CHW ( <i>n</i> = 4)	Total ( <i>n</i> = 35)
Child's sex, <i>n</i> (%)				
Male	8 (47)	11 (79)	1 (25)	20 (57)
Female	9 (53)	3 (21)	3 (75)	15 (43)
Kidney diagnosis, <i>n</i> (%)				
CAKUT	9 (54)	5 (36)	3 (75)	17 (48)
Polycystic kidney disease	1 (6)	0	0	1 (3)
Nephrotic syndrome	0	7 (50)	0	7 (20)
Reflux nephropathy	3 (18)	0	0	3 (9)
Acute glomerulonephritis	2 (12)	1 (7)	1 (25)	4 (11)
Other	2 (12)	1 (7)	0	3 (9)
Child's age group, <i>y</i> , <i>n</i> (%)				
0–4	7 (41)	3 (21)	2 (50)	12 (34)
5–9	5 (29)	4 (29)	0	9 (26)
10–14	1 (6)	2 (14)	1 (25)	4 (11)
14–19	4 (24)	5 (36)	1 (25)	10 (28)
Dialysis vintage, <i>mo</i> , <i>n</i> (%)				
<6	5 (29)	1 (7)	0	6 (17)
6–12	2 (11)	4 (29)	1 (25)	7 (20)
12–60	9 (53)	7 (50)	3 (75)	19 (54)
>60	1 (6)	2 (14)	0	3 (9)
Dialysis modality, <i>n</i> (%)				
PD	9 (47)	1 (7)	1 (25)	11 (31)
Hemodialysis	8 (53)	13 (93)	3 (75)	24 (69)

CAKUT, congenital anomalies of the kidney and urinary tract.

constructive, affirming perspective and reframe dialysis as necessary for life, or as a part of life, rather than unnatural or something to get through (Table 4, quote 5).

Caregivers who accepted dialysis recounted no longer thinking in terms of burdens. Rather, they tried to stay positive and focus on solutions and enjoying the moment. These caregivers noted that although the requirements of dialysis treatment are burdensome, their child is never a burden (Table 4, quote 6).

Those caregivers who were less able to accept life with dialysis reported the experience of having a child on dialysis as unnatural. They compared their current experience with their previous life with a healthy child, to what life could be if they had a healthy child, or to what they anticipated life might be after a transplant (Table 4, quote 7). They described their current life and limitations as much more burdensome and negative (Table 4, quote 8).

### Personal Growth

Caregivers described developing a range of coping strategies for improving and maintaining self-care. These strategies included adaptive behaviors, such as mindfulness, exercise, relaxation, and reliance on faith but also less adaptive mechanisms, such as gallows humor and emotional eating resulting in significant weight gain or chronic medical conditions (such as hypertension, diabetes, depression, or anxiety) because of their caregiving stresses (Table 4, quotes 9 and 10). Others reported acquiring wisdom and insight through their experiences allowing them to cope in the longer-term, appreciate the little things, and undertake a more holistic approach to life and caregiving (Table 4, quote 11).

### Medical Stress and Psychological Burden

Caregivers experienced significant stress, directly and vicariously, with little opportunity for respite. They described lasting psychological

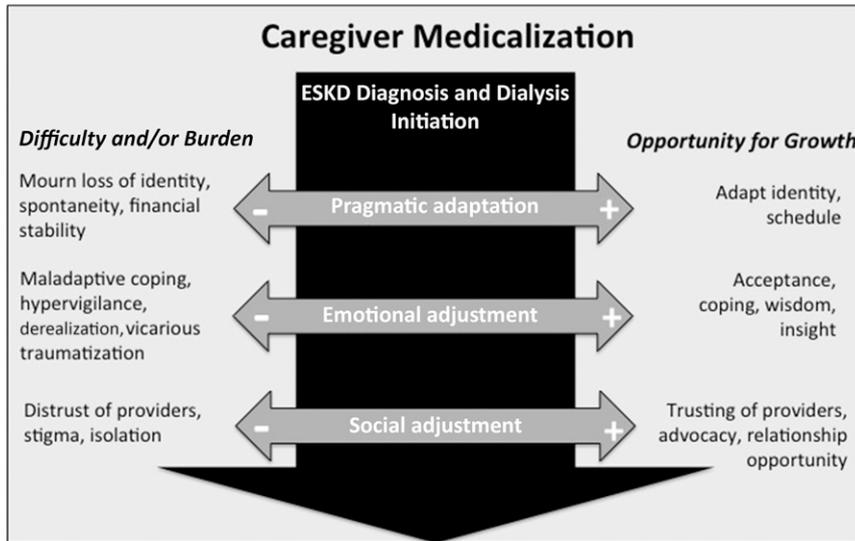
burdens from experiences such as witnessing their child in critical condition or undergoing painful procedures or believing or being told their child was going to die (Table 4, quote 12). These stressors were chronic and were compounded by feelings of grief, guilt, or powerlessness. For some, this stress led to maladaptive behaviors, including hypervigilance about their child's health status to the point that it created an adversarial relationship with the dialysis staff (Table 4, quote 13). Others described feeling detached and dissociated from their experience (Table 4, quote 14).

### Pragmatic Adaptation

Caregivers described needing to adjust to the upheaval, responsibilities, and added stressors (particularly financial) of everyday life to accommodate caring for their child.

### Disruption

Caregivers reported that their families adopted a regimented lifestyle with little room for breaks in



**FIGURE 1** Dialysis caregiver experience. The thematic schema represents caregiver perspectives on caring for a child with ESKD on dialysis. The theme of caregiver medicalization is the milieu that underlies and influences the themes of pragmatic adaptation, emotional adjustment, and social adjustment, although the experience of medicalization is dynamic and ever changing and therefore is influenced by the other themes and the child's medical status. The diagnosis of ESKD and initiation of dialysis is an inflection point for caregivers with subsequent experiences occurring on a spectrum ranging from more difficult and burdensome experiences that can arise (left) or positive experiences and the opportunity for growth (right).

the daily routine of diet, medications, and dialysis for spontaneity or a vacation (Table 5, quote 1). Caregivers also expressed worry and frustration that the limitations imposed by their child's chronic disease, such as missing school or other childhood activities, interfered with their child experiencing a typical childhood (Table 5, Quote 2).

#### *Adaptation of Life Goals and/or Sense of Self*

With the initiation of dialysis, caregivers reported that their own goals and life plans were interrupted as focus shifted to managing their child's dialysis. This included being forced to give up valued pursuits, such as obtaining an education, advancing in a career, or pursuing a romantic relationship (Table 5, quote 3). They also described facing societal expectations that they should be employed and the stigma associated with being unable to earn a wage (Table 5, quote 4).

Caregivers in relationships described a change in their role within the family from partner or wage earner to caregiver exclusively (Table 5, quote 5). This reversion was isolating, resulting in loss of social connections outside the family (Table 5, quote 6). Caregivers also reported that the roles of their other children can be changed because they may be deputized to act as "mini parents," enforcing the diet, fluid, and activity restrictions on the sibling with ESKD (Table 5, quote 7).

#### *Financial Impact*

Among families with 2 caregivers, caregivers reported that 1 would relinquish work to focus on their child's medical needs. Caregivers described regularly encountering financial challenges in the setting of caring for their child on dialysis. They noted difficulties with out-of-pocket household expenses, such as gas, car maintenance, parking, healthier food, job loss, incomplete insurance coverage, copays, and medications

not covered by insurance (Table 5, quote 8). Caregivers struggled with being uninsured or unable to pay for their own medical bills (Table 5, quote 9).

Caregivers recounted difficulty paying for their child's medical expenses and were reliant on Medicaid coverage for support. Caregivers felt they could not work or advance in their career because earning a higher salary placed the child at risk for no longer qualifying for Medicaid, effectively placing the family in a financially untenable situation (Table 5, quote 10). Families who obtained private insurance reported struggling with high medication copays and deductibles (Table 5, quote 11). These struggles led to financial uncertainty and forced caregivers to make trade-offs with their limited resources; weighing the costs of their child's medical care against the needs of other children and other expenses (Table 5, quote 12).

#### **Social Adjustment**

Caregivers reported experiencing fundamental changes in their existing relationships and also reported opportunities for developing new sources of social connections and support.

#### *Relationship Opportunity*

Caregivers described developing strong relationships with other caregivers of children on dialysis. This was particularly apparent among caregivers of children on hemodialysis because of the shared time spent in the unit (Table 6, quote 1). Caregivers recounted attempting to connect to other dialysis families through the Internet, often with mixed results (Table 6, quote 2). Relationships with the dialysis staff, especially the nurses, were heavily relied on for friendship, humor, and support (Table 6, quote 3).

Caregivers who expressed trust in the medical team viewed their time spent in the medical environment as a time

**TABLE 3** Illustrative Quotations for the Caregiver Medicalization Theme

No.	Quote
Subtheme: diagnosis and initiation	
1	"You don't remember at the time because you are shocked and you are, like, in a shadow; you can't think at that moment because it's just bombarded with all this bad information" (Participant 6).
2	"[M]y child has kidney disease, now we need to find out a way that he can live, and then all of this stuff is thrown at me. I'm not a doctor, I'm not a nurse, I'm not, you know, I'm not any of those things. I'm an accountant. I have no idea what to do."
3	"Don't Google it. It's the worst of the worst online" (Participant 21).
4	"He was very much, like, '[S]he will need a transplant.' It wasn't, like, 'Well we think so.' Because I think parents cling to those words, like 'think' or 'maybe.' Those qualifying words. I like the very concrete if you know it" (Participant 32).
5	"It was a life-or-death situation to make that decision. So it was already made" (Participant 33).
6	"We were told that it was going to be very difficult and that they couldn't tell how we were going to deal with all of this. But we do all that we can because we want our baby. But we didn't realize that it was going to be so difficult, that she [was] going to need so much, that there were going to be so many doctors involved and so many medicines" (Participant 26).
7	"It was a deciding factor that we could do it at home, where [with] the hemodialysis we would have to go into the clinic, and that was just—there would have been even more strain than doing peritoneal dialysis at home" (Participant 25).
Subtheme: disease management	
8	"Trying to tell a 7-year-old she can't have a chicken nugget is like taking away her lifespan" (Participant 30). "It's a hard, tiring job because it's an everyday process. It's not a job for someone that want[s] to have pretty fingernails, or you want to be around in heels all the time. ... It's a workout job. It's a job that you really have to focus on, put your mind, heart into it. ... It's a job that you have to give up just about your everyday life by focusing in on this. It's not a job that you could say, "Oh I'll be ready in 15 minutes." It's not like that. It's very hard. It's tiresome" (Participant 32).
9	"I'm a nervous wreck because I've seen him go from walking around skipping and hopping to laid out in 1 day. So it's a nervous feeling that you have while they're on the machine. Like, 'Okay, he should be all right. He should be all right.' And, 'Lord, have mercy. Is he okay?'" (Participant 4)
Subtheme: the future	
10	"There is no outcome unless you get a transplant. You do dialysis, or you die. So I wouldn't really say there's an outcome" (Participant 23).
11	"Not knowing what the future is for him, I don't care if he has dialysis forever as long as forever is a long time..."(Participant 5).
12	"I can't think about him being in his thirties because I don't even know if he's going to make it to his teens" (Participant 14).
13	"[W]e just went through an adult unit...there's a bunch of looney tunes in those. The adults are usually older people. They're not youngsters. We're not talking 40-year-olds or 50-year-olds. These are the 60s, 70s, and 80s. And in adult units, they don't allow the parents to be sitting next to [the child] while going through the procedure. He's with other people that are a lot older. He's seeing a whole different society of older people on dialysis that are on the ends of their life rather than the beginning of his life, like he is. And that is a real problem, right there" (Participant 5).
14	"After transplant, we can get back to life" (Participant 17). "I don't make any plans for the future yet, until she gets a kidney and she's healthier. I just don't look to the future. I just live 1 day at a time" (Participant 18).

of respite, support, understanding, and friendship (Table 6, quote 4). Conversely, caregivers who reported distrusting the medical team were unable to accept support from the dialysis staff and described their experiences in the medical environment as stressful, isolating, and stigmatizing (Table 6, quote 5).

#### Advocacy

Caregivers described themselves as advocates for their child with the medical staff, insurance companies, or school personnel. Caregivers also

emphasized their desire to teach their child to self-advocate, to empower other caregivers to speak to the medical team, and to advocate for other patients by reminding them to take their medications or stay in school (Table 6, quote 6). In addition, caregivers also expressed a desire to create large-scale community or societal change to benefit other children with chronic disease by starting foundations, changing laws, or giving financially to the hospital or a research foundation (Table 6, quote 7).

#### Relationship Risk

Caregivers noted that the stresses, demands, and practical constraints of caring for a child on dialysis can alter or end relationships. The lack of a societal archetype for pediatric dialysis (as opposed to adult hemodialysis) and the requirements to adhere to a rigid schedule, for children to be kept in a clean environment, and of nightly home-based treatments for PD led to both physical and emotional isolation for caregivers (Table 6, quote 8).

**TABLE 4** Illustrative Quotations for the Emotional Adjustment Theme

No.	Quote
Subtheme: initial and/or acute phase	
1	"It has changed our lives. It changes everything. The life you had before, which was normal, your children are healthy, now this. We wonder why we have to deal with it" (Participant 31). "We wish we can be a normal family because we're not. It's not normal. It's not" (Participant 3).
2	"I feel bad and guilty. ... It's hard to be saying no all day, and you feel [like] the worst mom ever because they told you that" (Participant 13).
Subtheme: acceptance	
3	"I wasn't accepting. I didn't want to do what you guys all told me was necessary for her, but it wasn't an option. I didn't realize it at the time, but it's not an option" (Participant 16).
4	"His TPA got flushed instead of being pulled back, so there was a big hoopla about that. ... But as long as he doesn't die of anything, it doesn't matter, [because] everything is fixable" (Participant 23).
5	"As long as he's given his treatment, he's fine; he's living, who cares? ... The benefits is just life. I don't really have anything bad to say about it. I just accept it" (Participant 33).
6	"At this point, we've made it so far, and we're doing this; it's not like he's abnormal. It's just he needs a few, a little extra help. It's like plugging in your computer for an update every night. I take pride and responsibility when I plug him in. There's a difference between having your child's welfare in your hands and if it was someone else. Even if it were an adult, I still wouldn't be comfortable with it. But this is my baby, and I have to do this for him. He's my baby" (Participant 29). "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. Just turn it around. So we have to drive 2 hours or 4 hours 3 times a week. So I have my mom come along and we chat. So it's like that's not much different than if I had called you on the phone and we talked for 2 hours. Or let's go to a restaurant afterward, somewhere that we can't go to where we live. Something, a goal, like let's stop at the mall because it's better than the mall by us" (Participant 32).
7	"It was very difficult for us. It changed all our lives, the whole family. At the beginning I was really low and cried a lot" (Participant 31). "Mentally just having to deal with that, yeah, that's my kid. I made that. But what went wrong that I made it wrong? And now, we have to do all this extra stuff." "I have changed because of all the difficult things we've been through" (Participant 29).
8	"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" (Participant 10).
Subtheme: personal growth	
9	"Every day it's like a goal to reach when we come here. That's how I see it. So what I do is to pray a lot. I pray all will go well today, as well as we're going that we should return and that nothing will happen and the 3 hours that we are here that everything will go well. That's what I always do" (Participant 31).
10	"I didn't know I was a stress eater until I was faced with dialysis. I ate and ate and ate. And before I knew it, I gained 60–70 lb" (Participant 2). "I was under so much stress and so much pressure, and I didn't know why I had a headache; and once I found out, 'You have high blood pressure, and that's probably why your head is hurting all the time,' and it's pretty bad off, you know. And so now you're on medication, and so now you're still eating bad and you're taking medication, and you've gotta do something to change that because you're still not feeling better" (Participant 2). "I've gained a lot of weight from sitting. The weight issue has been a big problem for me because I almost had diabetes at some point" (Participant 24).
11	"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" (Participant 18).
Subtheme: medical stress and psychological burden	
12	"But if you were to show me a picture of her where she was [in the] NICU, I would start crying because then I remember the thing that happened back then" (Participant 26). "Okay, so I think this is going to be the end of it because there's not a lot we can do with her. ... We kind of kept her along, but things aren't going to go good. So my husband called me. He's like, 'You should come down here and see [the patient] before we would lose her'" (Participant 32).
13	"I have to be right here with him. I have to have my hand where the catheter enters his body, and I have to hold it firm. I am on point guarding him...watching out for all the little things that can hurt him" (Participant 19).
14	"It's surreal, but sometimes I think I'm dreaming, I'm still dreaming, and then I question and say, 'When am I going to wake up from this dream?' Then it's like, 'Okay. This is my reality.'... It's been 4 years, sometimes I feel like this is happening to somebody else. It's not really happening to me, and this is not me" (Participant 26).

TPA, tissue plasminogen activator.

Caregivers described stigmatization as multidimensional. It involved feeling judged by strangers, other parents, and the medical team

(Table 6, quote 9). Fear and perception of judgment by the medical team could impair communication, placing caregivers on

guard and preventing them from communicating freely with the medical team (Table 6, quote 10). Caregivers recounted that the stigma

**TABLE 5** Illustrative Quotations for the Pragmatic Adaptation Theme

No.	Quote
Subtheme: disruption	
1	“Hey, let’s take a break, it’s the summertime; let’s leave on Tuesday, and let’s not come back until Saturday.’ We miss those things. We were a water-park family, so we would visit water parks all the time. We miss those things” (Participant 2).
2	“Keeping him germ free, he can’t be around a lot of kids or go to school because of all the flu and colds. He’s not able to go a lot of places” (Participant 30).
Subtheme: adaptation of life goals and/or sense of self	
3	“Well, I’m 25. Before I was 25, I was supposed to be a nurse. So now I’m way behind. And now I don’t even know if that will even ever happen. A lot of our dreams have been canceled” (Participant 33). “Well now it’s more pursuing a job or career that makes money instead of trying to pursue a job or career that’s, like, a dream-type job. So it’s more of a means to an end instead of ‘Oh well I’m gonna try to go and do this because it’s what I want to do.’ It’s more about him now” (Participant 23).
4	“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...” (Participant 34).
5	“I’ve turned into a housewife and a caregiver that takes care of everything at home, and [my husband] does everything outside the home” (Participant 2).
6	“With the change and everything, here are these relationships for 15, 16 years that I’d had. I see these people every day, then all of a sudden [they are] gone. They’re not a part of my life anymore. There’s not a day where I wouldn’t talk to them. So now I’m in a whole new environment, and I don’t have that relationship with all these people that I did there. So it was a loss of identity and a loss of a support system” (Participant 4).
7	“She’s like, ‘Mommy [the child is] in the kitchen’ or ‘No [the child] cannot have none of that; don’t give nothing to [the child].’ She’s 5” (Participant 3).
Subtheme: financial impact	
8	“The groceries [cost] is high because I am getting certain things. I have to switch to a lot of stuff that he needs that are more healthy. And that’s a shame; they want you to eat healthy, but that stuff is so expensive” (Participant 35). “Parking [is] \$12 every time we come. ... Today I came, and we had to be here at 9:00, so we’re here at 9:00. But then there were issues at work. So now I had to leave to go handle things, and I was only gone for an hour. Now I’m back, and I’m going to have to pay another \$12. So today, [it was] \$24” (Participant 10).
9	“I don’t have insurance; most of the parents here [do not] have insurance” (Participant 6).
10	“I see all the parents struggling with private insurance. ... I told my husband I want him to stay where he’s at right now because I don’t want to struggle with no medicals. ... I prefer not to have a lot of money” (Participant 3).
11	“With him being on dialysis, if he runs a fever, I have no option but to bring him to the emergency department. Even having private insurance, that’s expensive when you look at that huge copay, but I don’t have another option because this is protocol...there’s medications that they need, and the copays are huge. ... So when it comes down to our out-of-pocket expenses, those aren’t things that we can afford because we are only on 1 income” (Participant 2). “[I]t’s a big long process of, ‘Well, I don’t want to pay,’ and ‘I don’t want to pay,’ and ‘I don’t want to pay’” (Participant 11).
12	“Because I’m in the negative, paying bills, paying the light bill, paying the mortgage, and this and that. Do I have enough gas to get here? Because the gas money, what Medicaid reimburses me for, mostly I used it for food. I mean, what can I do? I’m thinking to myself, ‘Okay, this is only temporary. She’s going to have a transplant soon.’ But it’s been, like, what, almost 5 years now? Because she’s going to be 6 pretty soon” (Participant 6). “Either get the medication or get the mortgage. Do this or pay the car insurance. And it’s like well I can’t ride around without car insurance, just like I can’t not pay my truck note because I need the vehicle. So it’s a balancing act when it comes to finances. ... It’s big” (Participant 2).

of chronic illness is compounded for families already struggling with other societal stigmas (eg, a marginalized minority or non-English speaking) or for those who are forced to rely on others for financial assistance (Table 6, quote 11). Pediatric dialysis was even considered taboo in some cultures (Table 6, quote 12). Finally, caregivers reported experiencing stigmatization vicariously through the experiences of their child (Table 6, quote 13).

### *Family Functioning*

Parenting roles and strategies were impacted by the demands of dialysis as well as the duty to meet the needs of others in the family. This included trying to maintain a sense of normalcy and routine despite the awareness that the struggle to maintain normalcy reflects the fact that life with a child on dialysis is not normal (Table 6, quote 14).

Caregivers reported that balancing the needs of their child who was sick against those of siblings was a source of stress and guilt. They recounted that prioritization of the child who was sick created tension and the potential for conflict, it but also created the opportunity for growth in siblings in that siblings were often empowered to act as caregivers for the sick child and through this process, they developed empathy (Table 6, quote 15).

**TABLE 6** Illustrative Quotations for the Social Adjustment Theme

No.	Quote
Subtheme: relationship opportunity	
1	"When I first came here, I had a group of moms. ... One of them, she taught me everything up here. So she's always going to be my friend. Then I have my new crew. ... Now, it's just, like, Facebook. Friday, 1 of the moms was like, 'Okay, so Facebook moms, I have to make a kidney cake. What am I feeding my kid? And then we're talking like that'" (Participant 7).
2	"I definitely wish there were more people to talk to, like other families that were in my same situation that I could relate to. ... I looked online to try to find dialysis patients or parents that are new, too, and there isn't much online either. So there's no support groups online or even just a chat group that we could chat about the things that worked and didn't work. There's none of that" (Participant 29).
3	"We have our moments, but you know they laugh all the time and be weird. I ask them pretty much what I would ask my own mom, you know, some questions and things. So they basically know everything about my life" (Participant 17).
4	"I think we get along really well. Even when [a nurse] comes up to the room in the ICU to do dialysis, it's not weird, and she's there for almost 3 hours. And it's actually something I look forward to, I'm like, 'Oh, good, it's like a friend is coming to hang out with me.' We can just talk about life, and we don't have to talk about just [the patient] and dialysis. So it's good. I always want to hear about [other nurse's] daughter. We get along really well" (Participant 32).
5	"For me, it wasn't, they would say that it felt like a family here for a everyone, but I didn't feel that this was the case with me. I didn't feel it was like that. I felt like I was being pushed to the side, my worries and concerns weren't being heard" (Participant 31).
Subtheme: advocacy	
6	"Something else that I've been doing to try to help is make awareness about kidney disease with children because people don't talk about it because they don't know about it. ... I meet a lot of moms that's just fresh coming on. Their kids are older; some kids are younger. And they're looking scared. And I'm like, 'Look, I've been doing this 13 years, and you're going to go through A, B, C, D, E, F, G'" (Participant 7).
7	"I need to have time to myself to work, to just start advocating and changing the laws and the system for these medically fragile children. I would do it for any child because somebody has to make sure that these kids are being taken care of" (Participant 30). "When my daughter is well, I want to come here to help out. I want to be here. ... So when I start working, I'm going to help the hospital. My daughter [asked] me, 'Mommy, when are you going to help?' So I tell her, 'When I have work. I will not be giving a lot, but I will get.' Because when you are in a situation like this, you need assistance, not only economically, but I also want to help by talking with people because you need that" (Participant 31).
Subtheme: relationship risk	
8	"The problem with most people is that they relate dialysis with adults. 'Oh my father's on dialysis.' 'My grandfather's on dialysis.' It's very different for a child" (Participant 5). "I think just people looking at you differently. They just push you off. They're just like they don't want to be part of this. ... It's almost like you have a plague or something. They don't know how to interact with you. Friends, family members...they don't know how to discuss or what questions to ask, so they just kind of avoid" Participant 18).
9	"Sometimes people will look at me weird, or they think I'm weird when I tell my kids in front, in the public, begging for water, and I tell her 'no'...but then if you say it in front of the public, it's like 'CPS'" (Participant 6).
10	"My fear is always, 'If I talk, then someone will take my kids'" (Participant 33).
11	"I feel that they help the people who speak English. And us, the Latin Americans, they don't help us. They don't give us assistance. I would see the social worker come to see other people but would not come to see me" (Participant 31).
12	"All my family, we are from Mexico, and in Mexico they have a taboo about dialysis. Dialysis is so different. When you hear something about dialysis, it's like, 'Oh, that's final'" (Participant 8).
13	"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?'" (Participant 3)
Subtheme: family functioning	
14	"That's pretty much 1 of the main burdens, just not being able to really give him any kind of normalcy" (Participant 14). "My husband and I and our other children, we try to carry out our lives as normal as we can. We do everything we can to make [our son] feel as normal as possible. We try not to make him feel bad about anything. And we just try to help him to be as normal as he possibly can be" (Participant 27).
15	"We have daughter. She was 4 months [old] when he was diagnosed, so I had to stop breastfeeding. I have to always leave her with somebody because she was too little for me to bring her, and 1 day I did, and it was hard. ... And, I mean, she had asked, 'Mommy, why are you always gone?' or 'Mommy, why are you always telling me things, and you don't tell [my other child]?' or 'Why do you always go and I don't go?'" (Participant 3)
Subtheme: intimate relationships	

**TABLE 6** Continued

No.	Quote
16	"I think it brought us closer [because] she needed me not as just a parent but as care provider" (Participant 16). "Close, I mean, we're just really, really close. He calls me mommy. I'm his mom. I'm his caregiver. I'm his love. He even comes up to me, and he'll bring out a little plastic ring, and he'll [say], 'Mom, will you marry me?'" (Participant 30)
17	"When things are tough, I know 100% that I can rely on [my wife], and she knows 100% she can rely on me. We know that the bottom line is that we all love each other a whole lot. We might get upset over some stupid thing, but the bottom line is, when things are tough, we know we can rely on each other 100%...the 2 musketeers, the 2 of us, supporting one another" (Participant 5).
18	"It's almost like, 'If you're not going to wrap your mind around what we got going on, then you can be over there.' So my marriage, it did, it split my marriage completely up. Because I felt like you need to grow up. I have to grow up. Our son is here. Nothing we can do but make sure he's okay. And if you're not going to be here to help him be okay, then I need you to be in here with the other ones. And if you can't do that, then I...I kind of did it by myself" (Participant 7).
19	"It strains us sometimes because it doesn't matter what day it is. It could be our anniversary. It could [be] my partner's birthday. It could [be] my birthday. It could be Christmas. ...And it's like, 'Oh, you got to go to dialysis.' But I've had relationships that didn't last because they felt like I had to always be with my kid, 'Oh, you're always with your son.' Like, 'Where am I supposed to be at if I'm not with him on dialysis?'" (Participant 7) "There's no sleepovers for mommy either. I can't do things a lot of people do because I don't have a sitter for her" (Participant 2).

CPS, Child Protective Services.

### *Intimate Relationships*

Caregivers reported that having a child with a life-limiting chronic medical condition impacted and could fundamentally alter the nature of their intimate relationships. This alteration could be positive (Table 6, quote 16), requiring that caregivers work as a team with their partner and fostering a stronger and closer relationship (Table 6, quote 17). This alteration could also be negative (Table 6, quote 18). Those without a partner noted that caregiver responsibilities limited their opportunities to find or maintain a new relationship (Table 6, quote 19).

### **DISCUSSION**

Thirty years ago, the ethicist Cynthia Cohen argued that infant dialysis should not be recommended in part because of the burdens placed on parents.<sup>7</sup> Cohen wrote, "What will be asked of parents will be more heroic than has ever been asked of parents before. They will become amateur intensivists in charge of what is, in effect, a home-based intensive care unit."<sup>7</sup> Despite numerous advances, 30 years later, the experience of

caregivers of children with CKD was still described as a "pervasive and profoundly negative experience."<sup>19</sup> This is consistent with studies of other pediatric chronic diseases requiring reliance on life-sustaining technology, which impose significant burdens on caregivers on whom much of the responsibility to administer treatments falls.<sup>28-31</sup>

In our project, caregivers also endorsed a burdensome experience that had physical, psychological, and financial tolls. Importantly, however, caregivers also described positive changes in their lives. The degree of positive changes seemed to be most influenced by caregiver acceptance of dialysis treatment and trust in the medical team.

Although Tong et al<sup>19</sup> found that most caregivers were able to accept their child's CKD, we found that acceptance of ESKD and the need for dialysis varied significantly among caregivers and occurred over time on a continuum. Caregivers able to accept these changes were able to meet the demands of their dual role and reframe their experience as a positive, lifesaving event for their child. This reframing is critical, permitting caregivers to adapt,

develop resilience, gain insight and new social supports, and become advocates for others experiencing chronic disease. Those unable to accept such circumstances struggled with grief over loss of their former identity and plans. Thus, they likely missed opportunity for growth.

Trust in the intentions of the medical team seemed to function like a prism, refracting all aspects of the caregiver experience. Trust influenced whether the extraordinary time spent in medical environments at home, the dialysis unit, or the hospital was perceived as supportive, friendly, places of respite, or places of heightened stress, stigma, and isolation.

The ability of caregivers to accept dialysis treatment and trust the medical team may be related to their ability to cope with traumatic stresses.<sup>32</sup> We found significant parallels between caregivers' experiences and those described in the integrative model of pediatric medical traumatic stress.<sup>32-34</sup> This is notable because pediatric medical traumatic stress may impact caregiver daily functions and readiness to meet the demands of medical care for children.<sup>33,34</sup>

Manifestations of this stress can include development of hypervigilance, derealization, and guilt over complications. This may explain the use of psychotropic medications among study caregivers and reflects previous research that 50% of parents of pediatric recipients of a kidney transplant in 1 cohort had symptoms of posttraumatic stress disorder.<sup>35</sup> These findings reveal a need to expand the role of multidisciplinary care (particularly psychological) provided to children with ESKD to better address the needs of primary caregivers. Practical concerns about billing for such services in a pediatric health care system will need to be addressed as well.

Despite the presence of the Medicare entitlement, we found that many caregivers were unable to work outside the home because of the demands of dialysis, underwent significant financial hardships and the need to ration resources, and lacked awareness of resources for respite.<sup>25</sup> This finding mirrors those of Medway et al<sup>25</sup> and others and reveals that the impact of the dramatic financial costs of dialysis treatment may be universal regardless of health care system.<sup>18,24,36</sup> Caregiver description of a perverse incentive to remain destitute to qualify for state-provided Medicaid insurance reflects a peculiarity of the American health care system. These expenses reinforce the importance of continued advocacy

by the nephrology community for the provision of resources to our patients and their families but also raise questions over how much expense is reasonable for a family to take on.

Our study has a number of important limitations that could impact generalizability of the findings. Although we were able to enroll a large number of caregivers, most were white mothers. Interpreter resources did not allow for interviews with caregivers other than those individuals who only spoke Spanish, and participating dialysis center census characteristics precluded us from obtaining an equivalent mix of caregivers with children undergoing hemodialysis and PD. Nevertheless, the relative proportion of white and African American race and Hispanic ethnicity among caregivers is similar to the proportion among pediatric recipients of dialysis according to the reports of the 2015 US Renal Data System<sup>37</sup> and the 2011 North American Pediatric Renal Trials and Collaborative Studies<sup>38</sup> data sets.

## CONCLUSIONS

Caregivers of children requiring chronic dialysis describe extraordinary burdens, and some also report acceptance and psychological growth. This experience varies significantly between individuals. This work underscores the importance of continued advocacy to support families with a child on

dialysis and of developing tools to allow for the study and development of targeted interventions to address caregiver burden in this population and the systematic study of the experience of children with CKD and their caregivers, such as the ongoing Health and Wealth in Children with Chronic Kidney Disease (K-CAD) Study.<sup>22,39</sup>

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## ABBREVIATIONS

CHW: Children's Hospital of Wisconsin  
CKD: chronic kidney disease  
ESKD: end-stage kidney disease  
PD: peritoneal dialysis  
SCH: Seattle Children's Hospital  
TCH: Texas Children's Hospital

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## REFERENCES

- Carey WA, Martz KL, Warady BA. Outcome of patients initiating chronic peritoneal dialysis during the first year of life. *Pediatrics*. 2015;136(3). Available at: [www.pediatrics.org/cgi/content/full/136/3/e615](http://www.pediatrics.org/cgi/content/full/136/3/e615)
- Carey WA, Talley LI, Sehring SA, Jaskula JM, Mathias RS. Outcomes of dialysis initiated during the neonatal period for treatment of end-stage renal disease: a North American Pediatric Renal Trials and Collaborative Studies special analysis. *Pediatrics*. 2007;119(2). Available at: [www.pediatrics.org/cgi/content/full/119/2/e468](http://www.pediatrics.org/cgi/content/full/119/2/e468)
- Wightman AG, Freeman MA. Update on ethical issues in pediatric dialysis: has pediatric dialysis become morally obligatory? *Clin J Am Soc Nephrol*. 2016; 11(8):1456–1462
- Teh JC, Frieling ML, Sienna JL, Geary DF. Attitudes of caregivers to management of end-stage renal disease in infants. *Perit Dial Int*. 2011;31(4):459–465
- Geary DF. Attitudes of pediatric nephrologists to management of end-stage renal disease in infants. *J Pediatr*. 1998;133(1):154–156
- Fauriel I, Moutel G, Moutard ML, et al. Decisions concerning potentially life-sustaining treatments in paediatric nephrology: a multicentre study in French-speaking countries. *Nephrol Dial Transplant*. 2004;19(5):1252–1257
- Cohen C. Ethical and legal considerations in the care of the infant with end-stage renal disease whose parents elect conservative therapy. An American perspective. *Pediatr Nephrol*. 1987;1(2):166–171
- Willig L, Paquette E, Hester DM, Warady BA, Lantos JD. Parents refusing dialysis for a 3-month-old with renal failure. *Pediatrics*. 2018;141(3):e20172096
- Zurowska AM, Fischbach M, Watson AR, Edefonti A, Stefanidis CJ; European Paediatric Dialysis Working Group. Clinical practice recommendations for the care of infants with stage 5 chronic kidney disease (CKD5). *Pediatr Nephrol*. 2013;28(9):1739–1748
- Bunchman TE. The ethics of infant dialysis. *Perit Dial Int*. 1996;16(suppl 1): S505–S508
- Lantos JD, Warady BA. The evolving ethics of infant dialysis. *Pediatr Nephrol*. 2013;28(10):1943–1947
- Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*. 2008;121(2):349–360
- Aldridge MD. How do families adjust to having a child with chronic kidney failure? A systematic review. *Nephrol Nurs J*. 2008;35(2):157–162
- de Paula ES, Nascimento LC, Rocha SM. Roles assessment in families of children with chronic renal failure on peritoneal dialysis. *Int J Nurs Pract*. 2008;14(3):215–220
- Brownbridge G, Fielding DM. Psychosocial adjustment to end-stage renal failure: comparing haemodialysis, continuous ambulatory peritoneal dialysis and transplantation. *Pediatr Nephrol*. 1991;5(5):612–616
- Tsai TC, Liu SI, Tsai JD, Chou LH. Psychosocial effects on caregivers for children on chronic peritoneal dialysis. *Kidney Int*. 2006;70(11):1983–1987
- Wiedebusch S, Konrad M, Foppe H, et al. Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. *Pediatr Nephrol*. 2010;25(8): 1477–1485
- Cimete G. Stress factors and coping strategies of parents with children treated by hemodialysis: a qualitative study. *J Pediatr Nurs*. 2002;17(4): 297–306
- Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Dev*. 2010;36(4):549–557
- Fielding D, Brownbridge G. Factors related to psychosocial adjustment in children with end-stage renal failure. *Pediatr Nephrol*. 1999;13(9): 766–770
- Laakkonen H, Taskinen S, Rönholm K, Holmberg C, Sandberg S. Parent-child and spousal relationships in families with a young child with end-stage renal disease. *Pediatr Nephrol*. 2014;29(2): 289–295
- Parham R, Jacyna N, Hothi D, Marks SD, Holttum S, Camic P. Development of a measure of caregiver burden in paediatric chronic kidney disease: the Paediatric Renal Caregiver Burden Scale. *J Health Psychol*. 2016;21(2): 193–205
- Reynolds JM, Garralda ME, Jameson RA, Postlethwaite RJ. How parents and families cope with chronic renal failure. *Arch Dis Child*. 1988;63(7):821–826
- Kiliś-Pstrusińska K, Wasilewska A, Medyńska A, et al. Psychosocial aspects of children and families of children treated with automated peritoneal dialysis. *Pediatr Nephrol*. 2013;28(11): 2157–2167
- Medway M, Tong A, Craig JC, et al. Parental perspectives on the financial impact of caring for a child with CKD. *Am J Kidney Dis*. 2015;65(3):384–393
- Watson AR. Stress and burden of care in families with children commencing renal replacement therapy. *Adv Perit Dial*. 1997;13:300–304
- Ledermann SE, Scanes ME, Fernando ON, Duffy PG, Madden SJ, Trompeter RS. Long-term outcome of peritoneal dialysis in infants. *J Pediatr*. 2000; 136(1):24–29
- Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics*. 2006;117(1). Available at: [www.pediatrics.org/cgi/content/full/117/1/e48](http://www.pediatrics.org/cgi/content/full/117/1/e48)

29. Mah JK, Thannhauser JE, McNeil DA, Dewey D. Being the lifeline: the parent experience of caring for a child with neuromuscular disease on home mechanical ventilation. *Neuromuscul Disord*. 2008;18(12): 983–988
30. Seear M, Kapur A, Wensley D, Morrison K, Behroozi A. The quality of life of home-ventilated children and their primary caregivers plus the associated social and economic burdens: a prospective study. *Arch Dis Child*. 2016;101(7):620–627
31. Falkson S, Knecht C, Hellmers C, Metzging S. The perspective of families with a ventilator-dependent child at home. A literature review. *J Pediatr Nurs*. 2017; 36:213–224
32. Neul SK. Medical traumatic stress symptoms in pediatric patients on dialysis and their caregivers: a pilot study. *Nephrol Nurs J*. 2012;39(6): 483–488; quiz 489
33. Price J, Kassam-Adams N, Alderfer MA, Christofferson J, Kazak AE. Systematic review: a reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *J Pediatr Psychol*. 2016;41(1): 86–97
34. Kazak AE, Kassam-Adams N, Schneider S, Zelikovsky N, Alderfer MA, Rourke M. An integrative model of pediatric medical traumatic stress. *J Pediatr Psychol*. 2006;31(4):343–355
35. Young GS, Mintzer LL, Seacord D, Castañeda M, Mesrkhani V, Stuber ML. Symptoms of posttraumatic stress disorder in parents of transplant recipients: incidence, severity, and related factors. *Pediatrics*. 2003;111(6, pt 1). Available at: [www.pediatrics.org/cgi/content/full/111/6/e725](http://www.pediatrics.org/cgi/content/full/111/6/e725)
36. Bello A, Sangweni B, Mudi A, Khumalo T, Moonsamy G, Levy C. The financial cost incurred by families of children on long-term dialysis. *Perit Dial Int*. 2018; 38(1):14–17
37. United States Renal Data System. *2017 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institutes of Diabetes and Digestive and Kidney Diseases; 2017
38. North American Pediatric Renal Trials and Collaborative Studies. *NAPRTCS 2011 Annual Dialysis Report*. Woburn, MA: North American Pediatric Renal Trials and Collaborative Studies; 2011
39. Wong G, Medway M, Didsbury M, et al. Health and wealth in children and adolescents with chronic kidney disease (K-CAD study). *BMC Public Health*. 2014;14:307

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