

Parental Perspectives on the Financial Impact of Caring for a Child With CKD

Meredith Medway, BLibStud (Psych Hons),^{1,2} Allison Tong, PhD,^{1,2}
Jonathan C. Craig, PhD,^{1,2} Siah Kim, FRACP,² Fiona Mackie, PhD,³
Steven McTaggart, PhD,⁴ Amanda Walker, MD,⁵ and Germaine Wong, PhD^{1,2}

Background: The economic consequences of chronic kidney disease (CKD) are severe for adult patients and their households, but the out-of-pocket expenses and economic burden of CKD and how this affects the caregivers of children with kidney disease are unclear. This study aims to describe parental perspectives on the financial impact of caring for a child with CKD.

Study Design: Face-to-face semistructured interviews.

Setting & Participants: Parents of children with CKD from 3 pediatric nephrology centers in Australia.

Analytical Approach: Transcripts were analyzed thematically.

Results: 27 parents of 26 children participated. We identified 5 themes: loss of freedom and control (prioritizing care, limiting occupational opportunities, and appreciating socioeconomic advantage), burden of sole responsibility (inability to rely on others, lack of respite, increased separation of family roles, and self-reliance), adapting for survival (vigilant budgeting, redefining normality and expectations, rechanneling resources to basic needs, and negotiating work flexibility), instability of circumstances (depleted capacity to work, unpredictability of child's health, burden of travel-related costs, imposition of debt, and domestic upheaval), and struggle in seeking support ("falling through the cracks" and unmet information needs).

Limitations: Few participants were fathers (n = 5), and results may not be transferable to non-English-speaking caregivers because these participants were excluded.

Conclusions: Parents focused their resources and attention on meeting the complex needs of their child. Inability to sustain employment due to focus on their child's care and both medical and nonmedical expenses were major contributors to the financial impact, with financial stress compounded by difficulties accessing government support. As a result, parents experienced profound financial and social instability and physical and psychological fatigue and exercised extreme financial vigilance. Increased access to respite and domestic support and financial and psychosocial interventions are suggested to minimize the financial impact of caring for a child with CKD, which in turn may lead to better care, quality of life, and health outcomes for children with CKD and their families.

Am J Kidney Dis. ■(■):■-■. © 2014 by the National Kidney Foundation, Inc.

INDEX WORDS: Pediatric; chronic kidney disease (CKD); end-stage kidney disease (ESKD); qualitative research; financial; economic; medical costs; health care expenditures; quality of life (QoL); caregiving; workforce participation; socioeconomic status (SES); Australia.

The mortality rate in children with versus without end-stage kidney disease is 30 times higher.^{1,2} Children with chronic kidney disease (CKD) report lower quality of life (QoL), which appears to be worse in patients who are socioeconomically disadvantaged.³⁻⁵ Further, children of lower socioeconomic status with CKD experience higher rates of comorbid conditions⁶ and poorer clinical outcomes.⁶⁻⁸

Caring for a child with CKD places significant physical, psychosocial, and financial stress on parents.⁹ Parents bear the responsibility of performing time-consuming technical procedures, such as peritoneal dialysis and supplemental enteral feeding, ensuring adherence to medication and to dietary and fluid restrictions, attending clinic appointments, and attending thrice-weekly 4- to 5-hour hemodialysis sessions, as well as advocating for their child's health care needs and providing continuous psychological support to help their child cope with the illness and treatment.^{9,10} Caregivers of children with CKD experience elevated levels of psychological distress and reduced

QoL,⁹⁻¹² and lower income has been found to be associated with decreased QoL among caregivers.¹⁰ This may affect the quality of care parents are able to provide, thereby affecting their child's health outcomes.^{10,11}

From the ¹Sydney School of Public Health, The University of Sydney, Sydney; ²Centre for Kidney Research, The Children's Hospital at Westmead, Westmead; ³Department of Nephrology, Sydney Children's Hospital, Randwick, NSW; ⁴Department of Nephrology, Royal Children's Hospital, Brisbane, QLD; and ⁵Department of Nephrology, Royal Children's Hospital, Melbourne, VIC, Australia.

Received March 18, 2014. Accepted in revised form July 28, 2014.

Address correspondence to Meredith Medway, BLibStud, Centre for Kidney Research, The Children's Hospital at Westmead, Westmead NSW 2145, Sydney, Australia. E-mail: meredith.medway@sydney.edu.au

© 2014 by the National Kidney Foundation, Inc.

0272-6386/\$36.00

<http://dx.doi.org/10.1053/j.ajkd.2014.07.019>

Financial difficulty has been identified as a significant contributor to the stress associated with caring for a child with CKD.⁹⁻¹¹ Health care costs and disruption to work are major contributors to economic hardship that families face.^{13,14} However, the particular financial stressors experienced by parents, the contribution of financial stress to their capacity to provide care for their child, and its influence on the parent's QoL are unclear. This study aims to describe the experiences, perspectives, and beliefs of parents caring for children on the financial impact of CKD. This may inform ways to minimize the financial impact and in turn improve QoL and health outcomes for children with CKD and their caregivers.

METHODS

Participant Selection

Participants were eligible if they were a parent/caregiver of a child with CKD stages 3 to 5, on dialysis therapy (5D) or had received a kidney transplant (5T), and were English speaking. Participants were recruited through The Children's Hospital at Westmead; Sydney Children's Hospital, Randwick; and the Royal Children's Hospital, Brisbane. Participants were purposively selected and identified by recruiting nephrologists to capture a range of socioeconomic status, geographic location, and ethnicity and their child's CKD stage, sex, and age. The study was approved by the Ethics Committees of the Sydney Children's Hospital Network and Children's Health Services Queensland.

Data Collection

A preliminary interview guide was developed based on a review of the literature on the experiences and perspectives of parents of children with CKD and other chronic illnesses, in particular the financial impact and financial coping with chronic illness.^{9,12,15-17} M.M. conducted a face-to-face semistructured interview with each participant at the hospital or at their home from April through September 2013. Recruitment ceased when theoretical saturation was reached; that is, when few or no new concepts were emerging in subsequent interviews. Interviews were digitally audiorecorded and transcribed.

Data Analysis

Transcripts were entered into the software HyperRESEARCH, version 3.0 (ResearchWare Inc), to aid in the storage, coding, and searching of the data. We drew from the principles of grounded theory, which is an approach for developing theory of social phenomena that is grounded in the data. Following this methodology in our analysis, M.M. conducted open coding by reading the transcripts line by line; examining, conceptualizing, and categorizing the data; and assigning codes to concepts. Axial coding and constant comparisons were applied by identifying relationships between concepts and exploring similarities and differences in the data to developed analytical themes.^{18,19} These were mapped into a thematic schema to illustrate the connections among themes. The transcripts were read by a second investigator, A.T., who reviewed the preliminary themes to ensure that the full range of experiences and perspectives reported by participants were included.

RESULTS

Recruitment and Participant Characteristics

Of the 32 parents/caregivers approached, 27 (84%) agreed to be interviewed. Participant characteristics are presented in [Table 1](#). The age range of participants was 29 to 56 (mean, 43.2 ± 6.8 [SD]) years, and 22 (82%)

Table 1. Characteristics of Parents

Characteristic	No. (%)
Age category	
20-<30 y	1 (4)
30-<40 y	8 (30)
40-<50 y	15 (56)
50-<60 y	3 (11)
Parent	
Mother	22 (82)
Father	5 (18)
Gross weekly income	
A\$0-599	8 (30)
A\$600-\$1,249	10 (37)
A\$1,250-\$2,000	1 (4)
>A\$2,000	8 (30)
Highest education level	
Primary	2 (7)
Secondary	13 (48)
Trade	3 (11)
Other certificate/diploma	1 (4)
Bachelor's degree/higher	8 (30)
Marital status	
Married/de facto	21 (78)
Divorced/separated	3 (11)
Single	3 (11)
Interview venue	
Hospital	13 (48)
Home	14 (52)
Geographical location	
Metropolitan	23 (85)
Rural	4 (15)
Distance to hospital	
0-10 km	8 (30)
11-20 km	7 (30)
21-40 km	5 (19)
41-80 km	1 (4)
>80 km	6 (22)

Note: N = 27.

were women. Characteristics of the children of participants are presented in [Table 2](#).

We identified 5 major themes: loss of freedom and control (prioritizing care, limiting occupational opportunities, and appreciating socioeconomic advantage), burden of sole responsibility (inability to rely on others, lack of respite, increased separation of family roles, and self-reliance), adapting for survival (vigilant budgeting, redefining normality and expectations, rechanneling resources to basic needs, and negotiating work flexibility), instability of circumstances (depleted capacity to work, unpredictability of child's health, burden of travel-related costs, imposition of debt, and domestic upheaval), and struggle in seeking support ("falling through the cracks" and unmet information needs). A thematic schema showing the key relationships between these themes and subthemes is displayed in [Fig 1](#).

Download English Version:

<https://daneshyari.com/en/article/6157258>

Download Persian Version:

<https://daneshyari.com/article/6157258>

[Daneshyari.com](https://daneshyari.com)