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Impact of Non-medical Out-of-pocket Expenses on Families of Children With Cerebral Palsy Following Orthopaedic Surgery

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ABSTRACT

Purpose: Limited research has been conducted on the non-medical out-of-pocket expenses (NOOPEs) incurred by families of children with chronic health conditions. The study objectives were to: 1) calculate the estimated NOOPEs incurred by families during hospitalization of their child, 2) identify predictors of high NOOPEs, and 3) assess the impact of the child's chronic health condition on the family's finances.
Design and Methods: Prospective observational study. Parents were included if their child was 3–20 years old, had severe, non-ambulatory cerebral palsy (CP), and scheduled for hip or spine surgery. Parents reported all NOOPEs incurred during their child's hospitalization using the Family Expense Diary. Families completed the subscales of the Impact on Family Scale and the Assessment of Caregivers Experience with Neuromuscular Disease. Descriptive and univariate and multiple hierarchical regression models were used in the analysis.
Results: Fifty two parents participated. The total NOOPEs ranged from $193.00 to $7192.71 (M = $2001.92) per hospitalization representing an average of 4% of the family's annual earned income. Caregiver age ($F = 8.393$, $p < 0.001$), income ($F = 7.535$, $p < 0.001$), and distance traveled to the hospital ($F = 4.497$, $p = 0.039$) were significant predictors of high NOOPEs. The subscale scores indicated that a child's chronic health condition had a significant impact on family finances.
Conclusions and Practice Implications: Hospitalization is associated with numerous NOOPEs that create additional financial demands for families caring for a child with severe CP. NOOPEs should be addressed when preparing families for their children's planned hospital admissions, especially those families of CSHCN who experience significant financial impacts secondary to their children's care.

Today's healthcare arena is increasingly emphasizing cost-sharing and cost shifting strategies in order to reduce healthcare system expenditures (Meyer, 2016). Families of children with chronic conditions are now bearing a sizable percentage of their children's healthcare costs (Dworetzky et al., 2017). Children with cerebral palsy (CP) are one such group. CP, a neurodevelopmental disorder, is the leading cause of chronic physical disability in childhood affecting 2 to 2.5 children per 1000 live births (Stanley, Blair, & Alberman, 2000). Children with CP often meet criteria for children with medical complexity (Cohen et al., 2011). Those on the severe end of the clinical spectrum, classified on the Gross Motor Function Classification System (GMFCS) as level IV or V, have marked physical, cognitive, and other developmental impairments and require lifelong, comprehensive caregiving (Hallum & Krumboltz, 1993; Rosenbaum et al., 2007; Stevenson, Pharoah, & Stevenson, 1997); these children meet the federal definition of Children with Special Health Care Needs (CSHCN) (McPherson et al., 1998). Caring for these children requires considerable financial expenditures that are exacerbated during periods of hospitalization (Brehaut et al., 2004; Murphy, Christian, Caplin, & Young, 2007).

Health insurance covers the majority of expenditures associated with hospitalization but not all of the costs. These out-of-pocket expenses (OOPEs) are categorized as medical or non-medical. Medical

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OOPEs include items such as over the counter medications, durable medical equipment, and therapies. Non-medical out-of-pocket expenses (NOOPEs) include costs that are directly attributed to providing care for the child by the family such as: healthcare related travel, food and lodging, dependent child and pet care, "docked" wages secondary to caregiving, and incidental expenses (Cohn, Goodenough, Foreman, & Suneson, 2003; DiFazio & Vessey, 2011, 2013).

These expenses inflate a family's overall OOP expenditures (Hayman et al., 2001; Moore, 1999); yet, there is little known about them. A small cadre of studies has attempted to capture the NOOPEs associated with pediatric hospitalizations, but they are dated, differ in the populations studied, had fewer expense categories, and used varied analytic methods and metrics (Callery, 1997; Cohn et al., 2003; Leader et al., 2003; McLoughlin, Hillier, & Robinson, 1993; Wasserfallen, Bossuat, Perrin, & Cotting, 2006). Moreover, most were conducted outside the United States, limiting cross-comparisons (Callery, 1997; Cohn et al., 2003; McLoughlin et al., 1993; Wasserfallen et al., 2006). Despite their importance in caregiving, NOOPEs are not regularly included in estimates of total healthcare costs or addressed by healthcare providers.

Purpose

The objectives of this study were to: 1) calculate the estimated total NOOPEs incurred by families during the hospitalization of their child as measured by the Family Expense Diary, expressed within the context of the percent of the family's annual income, 2) assess the impact of the child's chronic condition on the family's finances through financial impact self-report measures, and 3) identify predictors that contribute to incurring high NOOPEs.

Methods

Design

Institutional Review Board (IRB) approval was obtained. A single group prospective observational study design was used. NOOPEs data were collected as part of a larger study evaluating the effect of orthopaedic surgery on health-related quality of life in children with GMFCS IV–V CP and caregiver burden (Difazio, Vessey, Zurakowski, & Snyder, 2015).

Sample

In an attempt to capture all eligible families, participants were enrolled consecutively between February 2011 and December 2014 from a quaternary care pediatric medical center. Caregivers were included if their children were 3 to 20 years old, had GMFCS IV–V CP, scheduled for spine or hip surgery, and lived at home with their family.

Instruments

Demographics Form

A demographics form was used to collect background information about the patient, caregiver(s) and family. Variables appear in Table 1.

Family Expense Diary

The Family Expense Diary was used to capture the NOOPEs incurred by families during their child's hospitalization. The diary was adapted from previous related studies (Birenbaum & Clarke-Steffen, 1991; Leonard, Brust, & Sapienza, 1992), expert professional opinion (DiFazio & Vessey, 2011), and family input. NOOPEs were reported in seven categories of expenses including: 1) transportation, 2) lodging, 3) food, 4) dependent care, 5) housekeeping, 6) lost work hours, and 7) incidental expenses (Fig. 1). The diary was field tested with families whose children were hospitalized for orthopaedic surgery (DiFazio & Vessey, 2013) and was revised to improve the data quality.

Table 1
Patient, caregiver and family characteristics (N = 52).

Characteristics	N	(%)
Patient characteristics		
Age (years) (mean, SD)	11.5	±3.87
Sex		
Male	31	(59.6)
Female	21	(40.4)
Type of surgery		
Hip osteotomy	34	(65.4)
Spinal fusion	18	(34.6)
Race		
White	47	(85.5)
Black/African American	5	(9.1)
Ethnicity		
Hispanic	6	(11.5)
Not Hispanic	46	(88.5)
Length of stay in hospital: all patients (days) (mean/median; SD)	9.36/7.0	±6.83
Length of stay in hospital: hip patients (days) (mean/median; SD)	6.9/6.5	±2.78
Length of stay in hospital: spine patients (days) (mean/median; SD)	14/10	±9.49
Caregiver characteristics		
Relationship to child		
Biological parent	47	(90.4)
Adoptive parent	5	(9.6)
Sex		
Male	5	(9.6)
Female	47	(90.4)
Race		
White	49	(94.2)
Black/African American	3	(5.8)
Ethnicity		
Hispanic	5	(9.6)
Not Hispanic	47	(90.4)
Caregiver education		
Some high school or less	3	(5.8)
High school diploma/GED	12	(23.1)
Some college, vocational, or associates	13	(25)
College or university degree	14	(26.9)
Post graduate degree	10	(19.2)
Partner education		
Some high school or less	1	(1.9)
High school diploma/GED	7	(13.5)
Some college, vocational, or associates	12	(23.1)
College or university degree	16	(30.8)
Post graduate degree	10	(19.2)
Not listed	6	(11.5)
Caregiver work		
Full time	15	(28.8)
Part time	14	(30.8)
Homemaker	9	(9.6)
Not working due to child's health	11	(11.5)
Not working for other reasons	3	(19.2)
Partner work		
Full time	32	(61.5)
Part time	3	(5.8)
Homemaker	1	(1.9)
Not working due to child's health	4	(7.7)
Not working for other reasons	3	(5.8)
Not listed/no partner	9	(17.3)
Family characteristics		
Distance from hospital (miles) (mean, SD)	116.02	±273.89
Location of residence		
In state	34	(65.4)
Out of state	17	(32.7)
Out of country	1	(1.9)
Family income		
<$10,000	4	(7.7)
$10,000–$39,999	9	(17.3)
$40,000–$69,999	12	(23.1)
$70,000–$99,999	15	(28.8)
>$100,000	12	(23.1)
Family income by percent Federal Poverty Level (FPL)		
<100%	5	(9.6)
101–200%	14	(29.9)

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