

Financial Difficulties in Families of Hospitalized Children

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BACKGROUND: High costs of hospitalization may contribute to financial difficulties for some families.

OBJECTIVE: To examine the prevalence of financial distress and medical financial burden in families of hospitalized children and identify factors that can predict financial difficulties.

DESIGN, SETTING, AND PARTICIPANTS: Cross-sectional survey of parents of hospitalized children at six children's hospitals between October 2017 and November 2018.

MAIN OUTCOMES AND MEASURES: The outcomes were high financial distress and medical financial burden. Multivariable logistic regression identified predictors of each outcome. The primary predictor variable was level of chronic disease (complex chronic disease, C-CD; noncomplex chronic disease, NC-CD; no chronic disease, no-CD).

RESULTS: Of 644 invited participants, 526 (82%) were enrolled, with 125 (24%) experiencing high financial distress, and 160 (30%) reporting medical financial burden.

Of those, 86 (54%) indicated their medical financial burden was caused by costs associated with their hospitalized child. Neither C-CD nor NC-CD were associated with high financial distress. Child-related medical financial burden was associated with both C-CD and NC-CD (adjusted odds ratio [AOR], 4.98; 95% CI, 2.41-10.29; and AOR, 2.57; 95% CI, 1.11-5.93), compared to no-CD. Although household poverty level was associated with both measures, financial difficulties occurred in all family income brackets.

CONCLUSION: Financial difficulties are common in families of hospitalized children. Low-income families and those who have children with chronic conditions are at particular risk; however, financial difficulties affect all subsets of the pediatric population. Hospitalization may be a prime opportunity to identify and engage families at risk for financial distress and medical financial burden. *Journal of Hospital Medicine* 2020;15:XXX-XXX. © 2020 Society of Hospital Medicine

Rising US healthcare costs coupled with high cost-sharing insurance plans have led to increased out-of-pocket healthcare expenditures, especially for those who are low income or in poorer health.¹⁻⁷ Increased out-of-pocket expenditures can lead to "financial distress" (defined as the subjective level of stress felt toward one's personal financial situation) and to "medical financial burden" (defined as the subjective assessment of financial problems relating specifically to medical costs). Financial distress and medical financial burden (defined together as "financial difficulty") lead to impaired access and delayed presentation to care and

treatment nonadherence in hopes of alleviating costs.⁸⁻¹²

Between 20% and 50% of families with children requiring frequent medical care report that their child's healthcare has caused a financial difficulty.^{13,14} In addition to direct medical costs, these parents can also suffer from indirect costs of their child's care, such as unemployment or missed work.¹⁵⁻¹⁷ Along with these families, families who are low income (generally defined as living below 200% of the Federal Poverty Level) also have higher absolute and relative out-of-pocket healthcare costs, and both groups are more likely to have unmet medical needs or to delay or forgo care.¹⁸⁻²⁰ Medically complex children also represent an increasing percentage of patients admitted to children's hospitals^{21,22} where their families may be more vulnerable to worsening financial difficulties caused by direct costs and income depletion—due to lost wages, transportation, and meals—associated with hospitalization.²³

The hospitalized population can be readily screened and provided interventions. Although evidence on effective inpatient financial interventions is lacking, financial navigation pro-

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grams piloted in the ambulatory setting that standardize financial screening and support trained financial navigators could prove a promising model for inpatient care.²⁴⁻²⁶ Therefore, understanding the prevalence of financial difficulties in this population and potential high-yield screening characteristics is critical in laying the groundwork for more robust in-hospital financial screening and support systems.

Our primary objective was to assess the prevalence of financial distress and medical financial burden in families of hospitalized children. Our secondary objective was to examine measurable factors during hospitalization that could identify families at risk for these financial difficulties to better understand how to target and implement hospital-based interventions.

METHODS

We conducted a cross-sectional survey at six university-affiliated children's hospitals (Table 1). Each site's institutional review board approved the study. All participants were verbally informed of the research goals of the study and provided with a research information document. Need for written informed consent was determined by each institutional review board.

Study enrollment occurred between October 2017 and November 2018, with individual sites having shorter active enrollment periods (ranging from 25 to 100 days) until sample size goals were met as explained below. Participants represented a convenience sample of parents or guardians (hereafter referred to only as "parents"), who were eligible for enrollment if their child was admitted to one of the six hospitals during the active enrollment period at that site. To avoid sampling bias, each site made an effort to enroll a consecutive sample of parents, but this was limited by resources and investigator availability. Parents were excluded if their child was admitted to a neonatal unit because of difficulty in complexity categorization and the confounding issue of mothers often being admitted simultaneously. There were no other unit-, diagnosis-, or service-based exclusions to participation. Parents were also excluded if their child was 18 years or older or if they themselves were younger than 18 years. Parents were approached once their child was identified for discharge from the hospital within 48 hours. Surveys were self-administered at the time of enrollment on provided electronic tablets. Participants at some sites were offered a \$5 gift card as an incentive for survey completion.

The survey included a previously published financial distress scale (InCharge Financial Distress/Financial Wellbeing Scale [IFDFW])(Appendix).²⁷ A question in addition to the IFDFW assessed whether families were currently experiencing financial burden from medical care^{28,29} and whether that burden was caused by their child (Appendix) because the IFDFW does not address the source of financial distress. The survey also included questions assessing perspectives on healthcare costs (data not presented here). The survey was refined through review by psychometric experts and members of the Family Advisory Council at the primary research site, which led to minor modifications. The final survey consisted of 40 items and was professionally translated into Spanish by a third-party company (Idem

TABLE 1. Characteristics of Parent Respondents and Their Hospitalized Child

Characteristic	N = 526
Hospital, No. (%)	
Lucile Packard Children's Hospital Stanford (Palo Alto, CA)	153 (29)
Seattle Children's Hospital (Seattle, WA)	74 (14)
Primary Children's Hospital (Salt Lake City, UT)	68 (13)
Texas Children's Hospital (Houston, TX)	81 (15)
Cincinnati Children's Hospital Medical Center (Cincinnati, OH)	75 (14)
American Family Children's Hospital (Madison, WI)	75 (14)
Language of survey	
English	507 (96)
Spanish	19 (4)
Ethnicity, No. (%) ^a	
Not Hispanic/Latino	400 (76)
Hispanic/Latino	111 (21)
Unknown/Missing	15 (3)
Race, No. (%) ^a	
White/Caucasian	362 (69)
Asian	36 (7)
Black/African American	42 (8)
American Indian/Alaska Native	4 (<1)
Native Hawaiian/Other Pacific Islander	5 (1)
Other	62 (12)
Unknown/Missing	15 (3)
% Federal Poverty Level, No. (%) ^b	
≥400%	157 (30)
200%-399%	138 (26)
100%-199%	90 (17)
<100%	92 (17)
Prefer not to answer/Missing	49 (9)
Child's medical complexity, No. (%) ^a	
Complex chronic disease	225 (43)
Noncomplex chronic disease	143 (27)
No chronic disease	157 (30)
Missing	1 (<1)
Child's insurance, No. (%) ^a	
Public	244 (46)
Private	274 (52)
Deductible ^c >\$1,000/y	163 (31)
Self-pay	1 (<1)
Unknown/Missing	7 (1)
Financial distress score, mean (SD)	5.6 (2.1)
Financial distress category, No. (%)	
High	125 (24)
Not high	401 (76)
Average	262 (50)
Low	139 (26)
Medical financial burden, No. (%) ^d	
Yes	160 (30)
Related to hospitalized child	86 (54)
No	361 (69)
Missing	5 (1)

^aThis information was abstracted from electronic health records.

^bThis value was calculated based on reported annual household income and number of individuals living in the household.

^cThis was based on self-report.

^dChild-related and child-unrelated medical burden were mutually exclusive answers.

Translations). It was pilot tested by 10 parents of hospitalized children to assess for adequate comprehension and clarity; these parents were not included in the final data analysis.

Variables

The primary outcome variables were level of financial distress as defined by the IFDFW scale²⁷ and the presence of medical financial burden. The IFDFW scale has eight questions answered on a scale of 1-10, and the final score is calculated by averaging these answers. The scale defines three categories of financial distress (high, 1-3.9; average, 4-6.9; low, 7-10); however, we dichotomized our outcome as high (<4) or not high (≥4). The outcome was analyzed as both continuous and dichotomous variables because small differences in continuous scores, if detected, may be less clinically relevant. Medical financial burden was categorized as child related, child unrelated, and none.

Our secondary aim was to identify predictors of financial distress and medical financial burden. The primary predictor variable of interest was the hospitalized child's level of chronic disease (complex chronic disease, C-CD; noncomplex chronic disease, NC-CD; no chronic disease, no-CD) as categorized by the consensus definitions from the Center of Excellence on Quality of Care Measures for Children with Complex Needs (Appendix).³⁰ We assigned level of chronic disease based on manual review of problem lists and diagnoses in the electronic health record (EHR) from up to 3 years prior. At sites with multiple researchers, the first five to ten charts were reviewed together to ensure consistency in categorization, but no formal assessment of interrater reliability was conducted. Other predictor variables are listed in Tables 2 and 3. Insurance payer was defined as "public" or "private" based on the documented insurance plan in the EHR. Patients with dual public and private insurance were categorized as public.

Statistical Analysis

We estimated sample size requirements using an expected mean IFDFW score with standard deviation of 5.7 ± 2 based on preliminary data from the primary study site and previously published data.²⁷ We used a significance level of $P = .05$, power of 0.80, and an effect size of 0.5 points difference on the IFDFW scale between the families of children with C-CD and those with either NC-CD or no-CD. We assumed there would be unequal representation of chronic disease states, with an expectation that children with C-CD would make up approximately 40% of the total population.^{21,22,31} Under these assumptions, we calculated a desired total sample size of 519. This would also allow us to detect a 12% absolute difference in the rate of high financial distress between families with and without C-CD, assuming a baseline level of high financial distress of 30%.²⁷ Our goal enrollment was 150 parents at the primary site and 75 parents at each of the other 5 sites.

We fit mixed effects logistic regression models to evaluate the odds of high financial distress and polytomous logistic regression models (for our three-level outcome) to evaluate the odds of having child-related medical financial burden vs hav-

TABLE 2. **Multivariable Logistic Regression Modeling the Odds of High Financial Distress**

Variable ^a	High financial distress AOR (95% CI)
Child's medical complexity	
No chronic disease	Reference
Non-complex chronic disease	0.89 (0.51-1.55)
Complex chronic disease	1.61 (0.86-3.03)
Child's insurance payer ^b	
Private	Reference
Public	1.38 (0.66-2.89)
Deductible >\$1,000/y	
No	Reference
Yes	1.28 (0.57-2.87)
Ethnicity	
Not Hispanic/Latino	Reference
Hispanic/Latino	0.70 (0.38-1.29)
Race ^c	
White/Caucasian	Reference
Asian	0.70 (0.22-2.19)
Black/African American	0.74 (0.34-1.61)
Other	1.53 (0.73-3.22)
% Federal Poverty Level	
≥400%	Reference
200%-399%	7.40 (2.88-19.03)
100%-199%	16.04 (5.89-43.68)
<100%	28.98 (10.24-82.06)

Abbreviation: AOR, adjusted odds ratio.

^aValues of "unknown" were treated as missing, and these values were imputed.

^b"Self-payer" was included in "Private" category to ensure sufficient cell sizes for modeling.

^c"American Indian/Alaskan Native" and "Native Hawaiian/Other Pacific" were included in "Other" category to ensure sufficient cell sizes for modeling.

ing child-unrelated burden vs having no burden. We fit linear mixed effects models to evaluate the effect of chronic disease level and medical financial burden on mean IFDFW scores. Respondents who answered "I don't know" to the medical financial burden question were aggregated with those who reported no medical financial burden. Models were fit as a function of chronic disease level, race, ethnicity, percentage of Federal Poverty Level (FPL), insurance payer, and having a deductible less than \$1,000 per year. These models included a random intercept for facility. We also fit logistic regression models that used an interaction term between chronic disease level and percentage of FPL, as well as insurance payer and percentage of FPL, to explore potential effect modification between poverty and both chronic disease level and insurance payer on financial distress. For our models, we used the MICE package for multiple imputation to fill in missing data. We imputed 25 data sets with 25 iterations each and pooled model results using Rubin's Rules.³² All analyses were performed in R 3.5.³³

RESULTS

Of 644 parents who were invited to participate, 526 (82%) were enrolled. Participants and their hospitalized children were mostly

TABLE 3. **Multinomial/Polytomous Regression Modeling the Odds of Having Medical Financial Burden**

Variable ^a	Child-related burden AOR (95% CI)	Child-unrelated burden AOR (95% CI)
Child's medical complexity		
No chronic disease	Reference	Reference
Noncomplex chronic disease	2.57 (1.11-5.93)	1.99 (1.05-3.78)
Complex chronic disease	4.98 (2.41-10.29)	0.64 (0.33-1.26)
Child's insurance payer ^b		
Private	Reference	Reference
Public	0.57 (0.27-1.19)	1.33 (0.58-3.07)
Deductible >\$1,000/y		
No	Reference	Reference
Yes	1.37 (0.69-2.76)	0.92 (0.35-2.42)
Ethnicity		
Not Hispanic/Latino	Reference	Reference
Hispanic/Latino	1.95 (0.99-3.81)	1.22 (0.59-2.53)
Race ^c		
White/Caucasian	Reference	Reference
Asian	0.58 (0.19-1.82)	0.75 (0.20-2.73)
Black/African American	1.40 (0.53-3.70)	1.18 (0.48-2.86)
Other	0.71 (0.32-1.61)	0.85 (0.36-1.99)
% Federal Poverty Level		
≥400%	Reference	Reference
200%-399%	2.39 (1.24-4.61)	2.02 (0.89-4.60)
100%-199%	2.21 (0.96-5.11)	3.36 (1.38-8.20)
<100%	2.55 (1.05-6.17)	3.77 (1.46-9.78)

Abbreviation: AOR, adjusted odds ratio

^aValues of “unknown” were treated as missing, and these values were imputed.

^b“Self-payer” were included in “Private” category to ensure sufficient cell sizes for modeling.

^c“American Indian/Alaskan Native” and “Native Hawaiian/Other Pacific” were included in “Other” category to ensure sufficient cell sizes for modeling.

White/Caucasian (69%) and not Hispanic/Latino (76%), with 34% of families living below 200% FPL and 274 (52%) having private insurance (Table 1). Of the hospitalized children, 225 (43%) were categorized as C-CD, 143 (27%) as NC-CD, and 157 (30%) as no-CD. All participants completed the IFDFW; however, there were five missing responses to the medical financial burden question. Table 1 lists missing demographic and financial difficulty data.

Financial Distress

The mean IFDFW score of all participants was 5.6 ± 2.1, with 125 having high financial distress (24%; 95% CI, 20-28) (Table 1). There was no difference in mean IFDFW scores among families of children with different chronic disease levels (Figure). On unadjusted and adjusted analyses, there was no association between level of chronic disease and high financial distress when C-CD and NC-CD groups were each compared with no-CD (Table 2). However, families living below 400% FPL (annual income of \$100,400 for a family of four) were significantly more likely than families living at 400% FPL and above to have high financial distress. Families tended to have lower financial distress (as indicated by mean IFDFW scores) with increasing percentage of FPL; however, there were families in every FPL bracket who experienced high financial distress (Appendix Figure 1a). A secondary analysis of families below and those

at or above 200% FPL did not find any significant interactions between percentage of FPL and either chronic disease level (*P* = .86) or insurance payer (*P* = .83) on financial distress.

Medical Financial Burden

Overall, 160 parents (30%; 95% CI, 27-35) reported having medical financial burden, with 86 of those parents (54%) indicating their financial burden was related to their child's medical care (Table 1). Compared with families with no such medical financial burden, respondents with medical financial burden, either child related or child unrelated, had significantly lower mean IFDFW scores (Figure), which indicates overall higher financial distress in these families. However, some families with low financial distress also reported medical financial burden.

Adjusted analyses demonstrated that, compared with families of children with no-CD, families of children with C-CD (adjusted odds ratio [AOR], 4.98; 95% CI, 2.41-10.29) or NC-CD (AOR, 2.57; 95% CI, 1.11-5.93) had significantly higher odds of having child-related medical financial burden (Table 3). Families of children with NC-CD were also more likely than families of children with no-CD to have child-unrelated medical burden (Table 3). Percentage of FPL was the only other significant predictor of child-related and child-unrelated medical financial

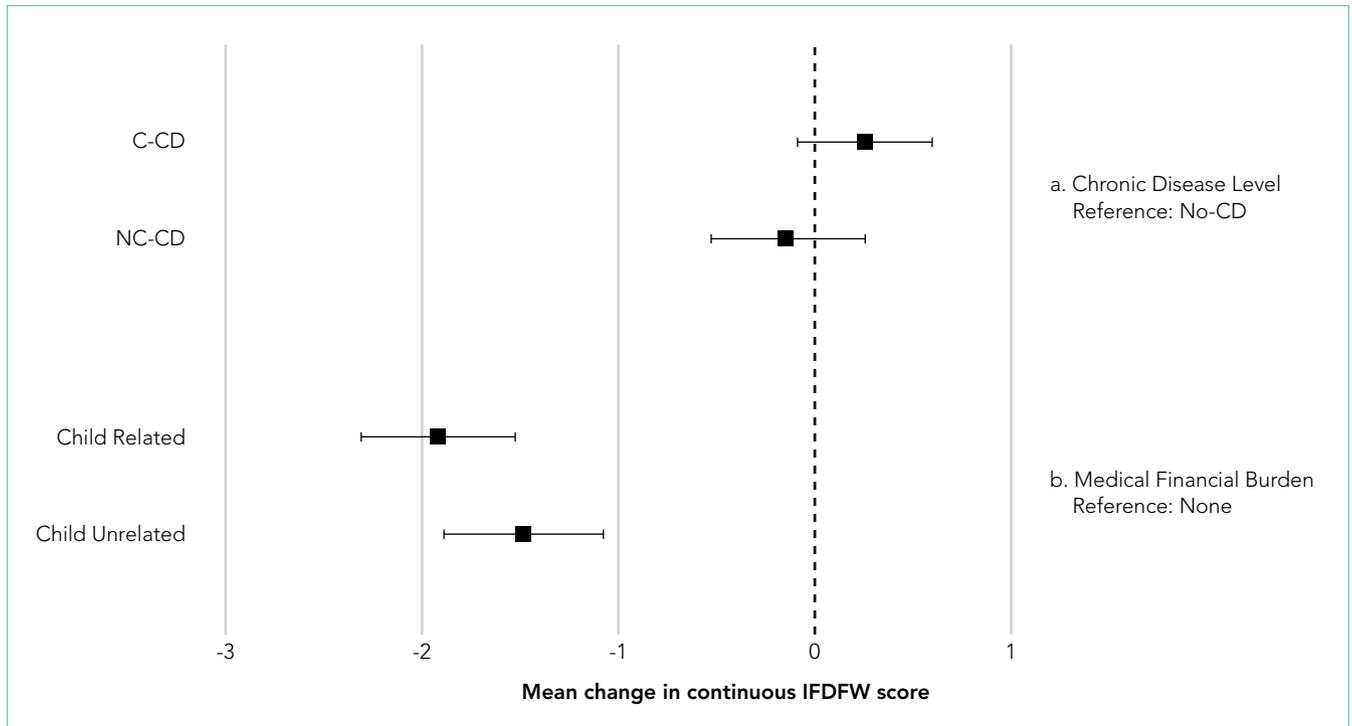


FIG. Mean Change in Continuous IFDFW Score Due to (a) Chronic Disease Level and (b) Medical Financial Burden. Negative values indicate lower IFDFW scores (corresponding to higher financial distress), and positive values indicate higher IFDFW scores (corresponding to lower financial distress). Bars indicate 95% confidence intervals.

burden (Table 3), but as with the distribution of financial distress, medical financial burden was seen across family income brackets (Appendix Figure 1b).

DISCUSSION

In this multicenter study of parents of hospitalized children, almost one in four families experienced high financial distress and almost one in three families reported having medical financial burden, with both measures of financial difficulty affecting families across all income levels. While these percentages are not substantially higher than those seen in the general population,^{27,34} 70% of our population was composed of children with chronic disease who are more likely to have short-term and long-term healthcare needs, which places them at risk for significant ongoing medical costs.

We hypothesized that families of children with complex chronic disease would have higher levels of financial difficulties,^{13,35,36} but we found that level of chronic disease was associated only with medical financial burden and not with high financial distress. Financial distress is likely multifactorial and dynamic, with different drivers across various income levels. Therefore, while medical financial burden likely contributes to high financial distress, there may be other contributing factors not captured by the IFDFW. However, subjective medical financial burden has still been associated with impaired access to care.^{10,34} Therefore, our results suggest that families of children with chronic diseases might be at higher risk for barriers to consistent healthcare because of the financial burden their frequent healthcare utilization incurs.

Household poverty level was also associated with financial distress and medical financial burden, although surprisingly both measures of financial difficulty were present in all FPL brackets. This highlights an important reality that financial vulnerability extends beyond income and federally defined “poverty.” Non-income factors, such as high local costs of living and the growing problem of underinsurance, may significantly contribute to financial difficulty, which may render static financial metrics such as percentage of FPL insufficient screeners. Furthermore, as evidenced by the nearly 10% of our respondents who declined to provide their income information, this is a sensitive topic for some families, so gathering income data during admission could likely be a nonstarter.

In the absence of other consistent predictors of financial difficulty that could trigger interventions such as an automatic financial counselor consult, hospitals and healthcare providers could consider implementing routine non-income based financial screening questions on admission, such as one assessing medical financial burden, as a nondiscriminatory way of identifying at-risk families and provide further education and assistance regarding their financial needs. Systematically gathering this data may also further demonstrate the need for broad financial navigation programs as a mainstay in comprehensive inpatient care.

We acknowledge several limitations of this study. Primarily, we surveyed families prior to discharge and receipt of hospitalization-related bills, and these bills could contribute significantly to financial difficulties. While the families of children with chronic disease, who likely have recurrent medical bills,

did not demonstrate higher financial distress, it is possible that the overall rate of financial difficulties would have been higher had we surveyed families several weeks after discharge. Our measures of financial difficulty were also subjective and, therefore, at risk for response biases (such as recall bias) that could have misestimated the prevalence of these problems in our population. However, published literature on the IFDFW scale demonstrates concordance between the subjective score and tangible outcomes of financial distress (eg, contacting a credit agency). The IFDFW scale was validated in the general population, and although it has been used in studies of medical populations,³⁷⁻⁴¹ none have been in hospitalized populations, which may affect the scale's applicability in our study. The study was also conducted only at university-affiliated children's hospitals, and although these hospitals are geographically diverse, most children in the United States are admitted to general or community hospitals.³¹ Our population was also largely White, non-Hispanic/Latino, and English speaking. Therefore, our sample may not reflect the general population of hospitalized children and their families. We also assigned levels of chronic disease based on manual EHR review. While the EHR should capture each patient's breadth of medical issues, inaccurate or missing documentation could have led to misclassification of complexity in some cases. Additionally, our sample size was calculated to detect fairly large differences in our primary outcome, and some of our unexpected results may have resulted from this study being underpowered for detection of smaller,

but perhaps still clinically relevant, differences. Finally, we do not have data for several possible confounders in our study, such as employment status, health insurance concordance among family members, or sources of supplemental income, that may impact a family's overall financial health, along with some potential important hospital-based screening characteristics, such as admitting service team or primary diagnosis.

CONCLUSION

Financial difficulties are common in families of hospitalized pediatric patients. Low-income families and those who have children with chronic conditions are at particular risk; however, all subsets of families can be affected. Given the potential negative health outcomes financial difficulties impose on families and children, the ability to identify and support vulnerable families is a crucial component of care. Hospitalization may be a prime opportunity to identify and support our at-risk families.

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