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## Pediatric palliative care parents' distress, financial difficulty, and child symptoms

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## Abstract

**Context**—Parents of patients with a serious illness experience psychological distress, which impacts parents' wellbeing and, potentially, their ability to care for their children. Parent psychological distress may be influenced by children's symptom burden and by families' financial difficulty.

**Objectives**—This study examined the associations among parent psychological distress, parent-reported patient symptoms, and financial difficulty, seeking to determine the relative association of financial difficulty and of patient symptoms to parent psychological distress.

**Methods**—Cross-sectional study of baseline data for 601 parents of 532 pediatric palliative care patients enrolled in a prospective cohort study conducted at seven US children's hospitals. Data included self-reported parent psychological distress and parent report of child's symptoms and family financial difficulty. We used ordinary least squares multiple regressions to examine the association between psychological distress and symptom score, between psychological distress and financial difficulty, and whether the degree of financial difficulty modified the relationship between psychological distress and symptom score.

**Results**—The majority of parents were moderately to severely distressed (52%) or severely distressed (17%) and experienced some degree of financial difficulty (65%). While children's symptom scores and family financial difficulty together explained more of the variance in parental psychological distress than either variable alone, parental distress was associated more strongly, and to a larger degree, with financial difficulty than with symptom scores alone.

**Conclusions**—Parent psychological distress was associated with parent-reported patient symptoms and financial difficulty. Future work should examine these relationships longitudinally, and whether interventions to improve symptom management and ameliorate financial difficulties improve parental outcomes.

## Keywords

Pediatric Palliative Care; Parents; Psychological Distress; Financial Difficulty; Patient Symptoms

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Parenting a child with a serious, life-threatening illness who is receiving pediatric palliative care (PPC) takes an incredible toll on parents' health and wellbeing, and parents often experience high levels of psychological distress, anxiety, and depression.(1–3) Poorer psychological health over time may lead to lower parental quality of life and increased health care use(4–6), morbidity, and mortality.(7, 8) Poorer parent psychological health can impact other family members(5), and impaired family functioning can in turn negatively impact parents' psychological outcomes.(9, 10)

Prior research highlights two factors, among others, that influence parental psychological health: children's symptom burden and families' financial challenges. Children's symptom burden has been found to have short- and long-term effects on parents' psychological outcomes.(4, 11–13) Financial difficulty is also often reported by families of children with serious illness, including work disruptions, income loss, and household material hardships (HMH)(14, 15), adding further challenges to caring for a seriously ill child.(9, 10, 16)

Little empirical evidence exists to quantify the relationship between parent psychological health, child symptomatology, and family financial difficulties. Symptom burden in children with cancer, as perceived by parents, was correlated with parents' depressive symptoms, but potential associations between financial difficulty and parents' mental health outcomes were not assessed.(13) Another study found that, among children with cancer, child health-related quality of life was significantly lower in low-income families compared to higher-income families, but did not examine parental outcomes.(17)

We, therefore, examined the relationships among parent psychological distress (along with anxiety and depression), parent-reported child symptoms, and family financial difficulty among parents of children receiving PPC. We hypothesized that higher distress would be associated with higher levels of parent-reported patient symptoms and family financial difficulty. We also sought to determine the relative association of financial difficulty and of parent-reported patient symptoms to parent distress.

## METHODS

### Human Subjects Protections

All study participants provided written informed consent. Institutional Review Boards approved the conduct of this study in all hospitals involved.

### Study Design and Participants

We performed a cross-sectional analysis of baseline data from an on-going prospective cohort study (Pediatric Palliative Care Research Network SHARE Study) conducted at seven children's hospitals (Children's Hospital of Philadelphia, Boston Children's/Dana-Farber Cancer Institute, Seattle Children's, Children's Hospital and Clinics of Minnesota, Akron Children's Hospital, Children's of Alabama, and Texas Children's). Patients under 30 years of age receiving PPC services were eligible. Eligible participants were primary caregivers responsible for the patient (referred to as 'parent' in this paper, although may include biologic or adoptive/foster parents, as well as grandparents), at least 18 years old or a minor permitted by state law to consent for participation, and able to speak and understand English or Spanish.

Enrollment occurred April 2017 through December 2020. Monthly calls with SHARE site coordinators ensured consistency in participant recruitment, data collection, and study procedures. When applicable, both mothers and fathers were approached for participation to increase the traditionally low representation of fathers in PPC studies.(18)

**Data Collection**—Parents completed instruments in a clinical care setting or at home, with data recorded via paper- or internet-based forms (Research Electronic Data Capture, REDCap).(19, 20)

**Background information:** Parents reported demographic information for themselves and their child, including age, child's health insurance status, parents' educational attainment (dichotomized into some college or more than some college), parents' employment status, and household income (reported in 25 discrete categories, ranging from \$10,000 to

>\$150,000). Household income was adjusted for household size by dividing by the square root of the number of persons in the household and standardizing at a 3-person size household.(21) Complex Chronic Conditions (CCC's) were determined by matching patients to their data in the Pediatric Hospital Information System (PHIS; Children's Hospital Association, Lenexa, KS) administrative database. Diagnoses recorded as ICD-10-CM codes were used to identify whether participating patients had any of 12 different and not mutually exclusive CCC categories.(22, 23)

### Outcome Variables

**Parent psychological distress (primary):** Parents completed the Kessler-6 (K6), a 6-item psychological distress scale screening tool that has been validated among parents of ill children.(24, 25) Total psychological distress score (range, 0–24) of 5–12 indicates moderate distress, and scores of 13 or greater indicate serious distress.(26, 27)

**Parent anxiety and depression (secondary):** Parents completed the PROMIS® Adult Profile version 2.0, a validated 29-item self-reported measure including 4 items for depression and 4 items for anxiety.(28–30) Items were summed and standardized to yield t-scores for anxiety and depression using the “PROMIS Pediatric and Parent Proxy Profile Instruments” manual and scoring tables (“PROMIS Parent Proxy – 25 v2.0”).(31)

### Independent Variables

**Parent-reported assessment of child symptoms:** Parents completed previously adapted versions of the Memorial Symptom Assessment Scale (MSAS)(32–35), including the PQ-MSAS Proxy for parents of children 0–2 years old (20 symptoms) and the PQ-MSAS Proxy for parents of children 2 years and older (28 symptoms).(36) These versions of PQ-MSAS assessed the frequency (0, never; 1, almost never; 2, sometimes; 3, a lot; 4, almost always) and severity (0, none; 1, slight; 2, moderate; 3, severe; 4, very severe) of physical and psychological symptoms across the study age range. Wording changes were made to shift the respondent to be the parent as opposed to the patient (e.g. changing “During the past week did you. ...” to “During the past week did your child/teen...”). Additional response options (“Not Applicable” and “I Prefer Not to Answer”) were added to account for cases where the item could be difficult for parents to answer due to a child's age or cognitive ability and to make the items consistent with other study instruments. A child's total symptom score was the average of all symptom scores for that child, transformed into a 0 to 100 range.(23, 36)

**Family financial difficulty:** Based on prior research, parents reported the extent to which they experienced difficulty with paying bills over the prior 6 months: no difficulty at all (score 0), a little (1), some (2), quite a bit (3), and a great deal (4).(37) Adapting a measure from a previous study(15), parents were also asked whether they had experienced specific types or degrees of household material hardship (HMH), defined as unmet basic needs, including having to live with others (scored 0, no; 1, yes), inability to pay rent or mortgage on time (0, 1), receiving shut-off notices from utility companies (0, 1), having utilities turned off (0, 1), worrying that food would run out (scored 0, never true; 1, sometimes true; 2,

often true), and running out of food (0, 1, 2).(15) A composite HMH score was created by summing the values for these 6 questions (range 0 to 8).

## Analyses

Counts, proportions, means, and standard deviations were used to report parent and child demographic information and clinical outcomes. For household income only, we reported median income categories to ease comparison to national figures (typically reported as medians). T-tests (two-tailed), chi-squares, and ordinary least squares regressions were used to detect differences between demographic characteristics and psychological outcomes. Correlations were run between parent distress, anxiety, and depression.

For the main analysis, ordinary least squares multiple regression models tested the association of parental psychological distress to parent-reported child's total symptom score and family financial difficulty, first in univariable and then multivariable models (adjusting for children's age, and parents' age, sex, race, educational attainment). All models accounted for family-level clustering in cases where two parents of the same child participated. For improved interpretability, parental psychological distress and child symptom scores were standardized. Due to the low proportion of missing data, analysis handled missing data with listwise deletion. Likelihood ratio testing was used to compare models. All data management, analysis, and figure creation were performed using Stata 16.1 (Stata Corp; College Station, TX).

## RESULTS

### Parent and patient characteristics

Of 756 eligible participants, 601 (79.5%) parents of 532 patients agreed to participate and completed baseline instruments by July 2020.

The 601 parents had a mean age of 37.9 (SD 9.5) years, and 79.2% were female (n = 476), 76.5% White (n=459), and 86.5% non-Hispanic (n=520) (Table 1). Most (76.2%) were partnered or married (n=458), and 84.9% (n=510) completed at least some college, technical, or trade school. Over 35% (n=213) were employed full-time, and 15.1% (n=91) were on leave for the child's illness.

The 532 children were an average of 7.1 (SD 7.0) years old, were 53.2% male (n=283), had an average of 5.5 (SD 2.1) CCCs, and over 98% had at least one CCC designation (Table 2). No more than 5% of any variable was missing.

### Parent psychological distress

Kessler-6 scores (Figure 1) had a mean of 7.7 (SD 5.1). Approximately 17% of participants had scores at or above 13, indicating severe psychological distress, and 69% had a score of 5 or above, indicating moderate to severe distress. Kessler scores did not vary significantly by parent age, sex, educational attainment, race, or ethnicity (all p values >0.15), but were higher when income was low and financial difficulty was more severe (both p values <0.05). Psychological distress was highest among those experiencing "a great deal" of financial

difficulty, decreased as financial difficulty became less severe, and was lowest among those experiencing “no difficulty at all.”

### **Relationship of parent anxiety and depression to psychological distress**

Parents had a mean standardized **PROMIS anxiety** score of 59.9 (SD 10.1; minimum 40.3; maximum 81.6) and a mean standardized **PROMIS depression** score of 54.3 (SD 9.7; minimum 41; maximum 79.4). Anxiety and depression scores were highly correlated ( $r=0.71$ ;  $p<0.001$ ; supplemental file). Psychological distress scores were significantly correlated with anxiety ( $r=0.57$ ;  $p<0.001$ ) and depression scores ( $r=0.64$ ;  $p<0.001$ ).

### **Parent-reported child total symptom scores**

Of 20 possible symptoms, parents reported their children having a mean of 6.6 (SD 3.4) symptoms, with 96.8% having at least one symptom, including pain, lack of energy, irritability, drowsiness, and shortness of breath. Total symptom scores ranged from 0 to 63.8 (mean 19.3; SD 11.7). Mean symptom scores and symptom counts did not differ by children’s sex, race, or ethnicity (all  $p$  values $>0.05$ ); however, both score and count increased as children’s age at baseline increased (all  $p$  values $<0.001$ ).

### **Household income, financial difficulty, and material hardship**

The median reported unadjusted household income category was \$65,001 to \$70,000 per year (similar to the US national median(38)) and ranged from \$10,000 to \$150,000. Nearly 13.2% of the sample ( $n=79$ ) reported household incomes below \$20,000, which is below the \$21,960 national poverty line for a family of three. The median household income adjusted for household size was \$57,500 (IQR: \$29,047 to \$90,933), which is slightly lower than national data.(39)

At baseline, 31.0% ( $n=186$ ) of parents reported no financial difficulty, while 17.3% ( $n=104$ ) reported a little, 23.8% ( $n=143$ ) some, 12.3% ( $n=74$ ) quite a bit, and 10.8% ( $n=65$ ) a great deal of difficulty; 4.8% ( $n=29$ ) did not report. Financial difficulty varied significantly by parent race (Black and American Indian parents reported greater difficulty,  $p=0.02$ ), ethnicity (Hispanic parents reported greater difficulty,  $p=0.01$ ), educational attainment (participants with higher levels of education reported less difficulty,  $p<0.001$ ), employment status (participants who were unemployed or on leave for their child’s medical condition reported greater difficulty,  $p=0.01$ ), and household income (participants with larger household incomes reported less difficulty,  $p<0.001$ ).

Parents also reported experiencing HMH. Overall, composite HMH scores ranged from 0 to 8 (mean 1.03; SD 1.70), and the percent of parents who reported specific HMH categories ranged from 4.7% (“Home was not heated/cooled”) to 22.4% (“Worried that food would run out”) (Table 3). Most ( $n=176$ ) parents who reported not experiencing any financial difficulty did not report any form of HMH. Of the parents reporting some degree of financial difficulty and some form of HMH ( $n=368$ ), 33% reported difficulty paying rent or mortgage on time over the past 6 months, and 5.6% and 18% reported that food often ran out or sometimes ran out, respectively, over the past 6 months (Figure 2, bottom panel). In addition, 155

parents who answered “no” to all of the HMH questions experienced at least some financial difficulty.

Parental psychological distress levels were significantly associated with unadjusted household income, financial difficulty, and HMH (Table 3) (all  $p$  values  $< 0.05$ ). Of note, financial difficulty and composite HMH scores were significantly correlated ( $r = 0.67$ ,  $p < 0.01$ ; supplemental file).

### **Parent psychological distress, parent-reported patient symptoms, and family financial difficulty**

Because psychological distress, anxiety, and depression were highly correlated, the main analysis used distress as the main outcome of interest. Further, given the high correlation between the financial difficulty single item and the composite HMH score, the main analysis used financial difficulty as one of the two main predictors of interest, with the child’s symptom score being the other. Lastly, these two predictors were slightly but not statistically significantly associated (a one-point rise in the financial difficulty score was associated with a 0.06 increase (95% CI:  $-0.01$ ,  $0.13$ ) in the standardized child symptom score, which is to say an increase equal to 6% of 1 standard deviation of this score among these children,  $p = 0.12$ ).

In separate univariable models, parent psychological distress was strongly associated with child symptom score (a 1-SD increase in symptom score was associated with 0.26-SD (95% CI:  $0.18$ ,  $0.34$ ) increase in the Kessler score,  $p < 0.001$ ) and with financial difficulty (a 1-SD increase in financial difficulty score was associated with a 0.27-SD (95% CI:  $0.19$ ,  $0.35$ ) increase in the Kessler score,  $p < 0.001$ ). Of these two models, the one with financial difficulty explained more of the variance in parent psychological distress ( $R^2 = 0.074$ ) than did the model with child symptom score ( $R^2 = 0.068$ ).

In a single multivariable model, with no adjustment for other parent or child characteristics, parent psychological distress was strongly associated with both child symptom score (0.24-SD change, 95% CI:  $0.16$ – $0.32$ ,  $p < 0.001$ ) and with financial difficulty (0.25-SD change, 95% CI:  $0.17$ – $0.33$ ,  $p < 0.001$ ), and this model explained more variance in parent distress ( $R^2 = 0.131$ ) than did either of the univariable models to a statistically significant degree (likelihood ratio test comparing full model to both univariable models,  $p < 0.001$ ).

In multivariable models with adjustment for parent race, age, sex, educational level, and the child’s age, variation in parent psychological distress was again explained to a higher degree by the combination of child symptom score and financial difficulty ( $R^2 = 0.164$ ) than by models with either of these factors separately ( $R^2 = 0.094$  for symptom score model,  $R^2 = 0.096$  for financial difficulty model).

These results can be visualized graphically, modeling the financial difficulty score as distinct levels rather than as a continuous variable (Figure 3). This figure depicts that parents of children with the lowest symptom scores and in families with no financial difficulty are predicted to have a level of psychological distress that is 1.6 SD less than parents of children with the highest symptom scores and in families with a great deal of financial difficulty.

### Additional analyses

The supplemental file contains analyses using the PROMIS anxiety or depression score as the outcomes of interest yielded the same pattern of findings, whereby child symptom score and financial difficulty were both independently associated with parent psychological distress to statistically significant degrees, and financial difficulty was associated to a larger degree.

We also detail an analysis where the single-item financial difficulty score was replaced by the HMM composite score and found the same pattern of findings.

## DISCUSSION

In this cohort of 601 parents of children with serious illnesses receiving PPC, 69% of parents were moderately to severely distressed and 17% were severely distressed. Parents reported that their children experienced an average of 6.6 out of 20 symptoms, with total symptom scores ranging from 0 to 63.8 out of 100. Additionally, over 65% of parents reported experiencing “a little” to “a great deal” of financial difficulty. While parent-reported children’s symptom scores and family financial difficulty were associated with, and together accounted for greater variance in, parental psychological distress, parental distress was associated more strongly, and to a larger degree, with financial difficulty than with symptom scores alone.

Our findings are consistent with previous findings and provide further evidence for the impact of parent-reported children’s symptoms and families’ financial difficulty on parental mental health. Other studies observed the effects of children’s perceived disease burden(4, 11–13) and financial difficulty(9, 10, 40, 41) on parental mental health. Few studies, however, have explored the impact of clinical and socioeconomic factors together on parents.(40, 42) Our study is the first, to our knowledge, to compare the relative contributions of parent-reported children’s symptom burden and family financial difficulty levels to parental psychological distress in a sample of parents of children receiving PPC services across the full range of patient ages and underlying conditions.

Three main findings warrant further exploration. First, clinically-important (moderate to severe) levels of psychological distress were reported in nearly 70% of our parent sample, exceeding estimates from previous studies reporting psychological distress in 40% to 66% of parent participants.(6, 9, 10, 40, 42) For parents, addressing these high levels of psychological distress could reduce physical and mental health care use(10), improve quality of life and wellbeing(6), and potentially reduce morbidity and mortality from stress-associated health conditions.(7, 8) For children, improving parents’ distress may improve child psychosocial functioning and reduce non-routine health care use.(10) Improved psychological distress may also improve caregivers’ cognitive functioning(43, 44), which could benefit parents’ ability to care for their child. Parents’ mental health symptoms have also been found to affect siblings’ mental health outcomes.(45) Finally, improving parent psychological health may benefit the entire family by mitigating the impact of children’s illnesses on families(10, 46) and improving family functioning.(10)



Second, for parents in our study, psychological distress was associated more strongly, and to a larger degree, with financial difficulty than with parent-reported child symptom scores. The few studies examining contributions of children's clinical outcomes and families' financial factors on parents' mental health did not compare the relative associations of these factors(42), relied on recall of these factors among bereaved parents(40), used broad measures of children's quality of life(40), or focused on only one disease group.(40, 42) Our findings are generalizable to the broader, heterogeneous population of children receiving PPC services since our participants represent various ages, underlying conditions, and disease onset and pace of progression, all of which may result in different care experiences and illness trajectories, in turn affecting parents' employment and family financial and material resources differently.(47–50)

Third, our findings have important implications for clinical practice. Future intervention-based research is needed to better understand how to screen for and mitigate financial difficulty and material hardships for families of children with medically-complex serious illnesses, as well as for families from marginalized and underserved communities who may be at greater risk for socioeconomic disadvantage and, thus, psychological distress.(51) Interventions may provide support focused on material conditions (e.g., financial counseling, direct income supplementation, charitable funds, food and housing assistance programs, child care supplements)(15, 47, 48), psychological response to financial hardship (e.g., counseling to cope with stress)(47, 48, 52), and coping behaviors related to financial hardship (e.g., reduced spending, finding lower cost medications and medical supplies). (52, 53) Greater involvement of PPC providers, particularly psychosocial providers, in the systematic screening for and facilitation of support for these families is therefore imperative. (15)

Our study is among the few investigating the impact of financial difficulty and HMH on child and family outcomes in PPC(15, 17, 54), particularly among a large and diverse clinical, geographic, and socioeconomic cohort. Additionally, our study used a single-item subjective measure of financial difficulty that may provide a comprehensive view of financial challenges across income levels. Several families in our study reported some financial distress without reporting any HMH, suggesting that the perception of financial distress may extend beyond these specific hardships. We propose that the measure of perceived financial difficulty be used to screen for potential financial challenges, and further assessment could be conducted into specific areas of need (e.g., HMH or other areas like difficulty paying medical bills).

Our study has several limitations. First, we cannot evaluate causality because of the cross-sectional study design. Consequently, we do not know if a child's illness caused financial difficulty (e.g., time taken off work to care for the child; employment loss or high medical bills due to the child's illness), or if the financial difficulty was present, independent of the child's illness. Along the same line of thought, we don't know if a child's symptoms caused the parent's psychological distress, the parent was distressed before the child had burdensome symptoms, or if a parent who is more distressed is more likely to perceive their child's symptoms to be more severe/burdensome than a parent who is less distressed at baseline. Second, our study sample, while diverse, does not fully match national race and

ethnicity characteristics, which could limit the generalizability of our findings. Third, our study measures may have excluded other factors potentially associated with psychological distress (e.g., pre-existing mental health conditions, perceived social support, access to mental health services).

## Conclusion

We found that parent psychological distress was associated with parent-reported children's symptoms and families' financial difficulty in a large cohort of parents of children receiving PPC. Future longitudinal investigations should evaluate the temporal relationships between parental distress, financial difficulty, and children's illness. Lastly, future intervention-based research should explore whether, and which, financial interventions can decrease psychological distress in parents of seriously ill children.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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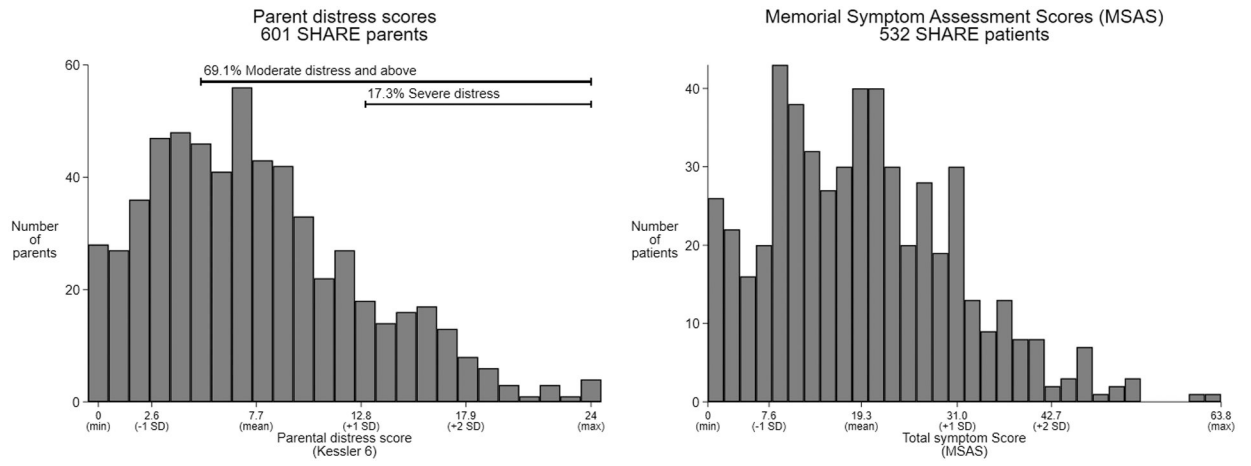
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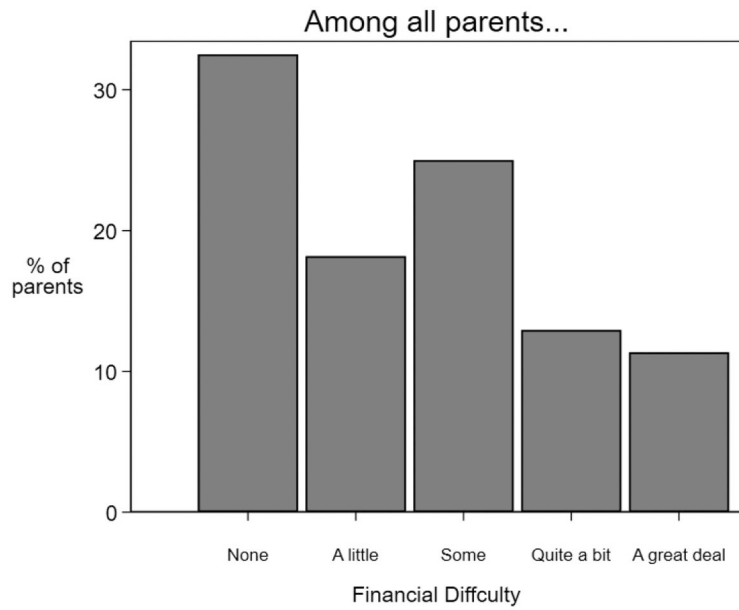
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**Key Message:**

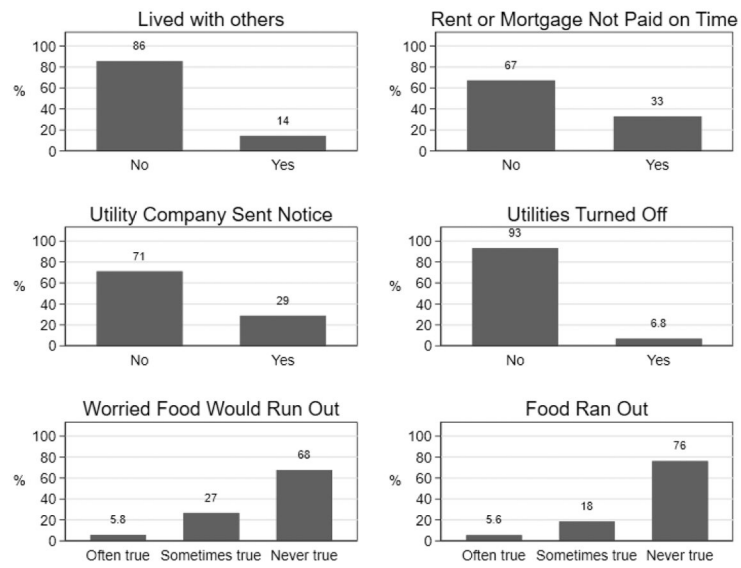
In the setting of pediatric palliative care, higher parent psychological distress was associated with family financial difficulty and patient symptom burden. Future work should explore the longitudinal relationship between these variables and whether greater financial support and better symptom management reduces parent psychological distress and improves patient and family outcomes.



**Figure 1.** Distribution of parent psychological distress scores and parent-reported child total symptom scores

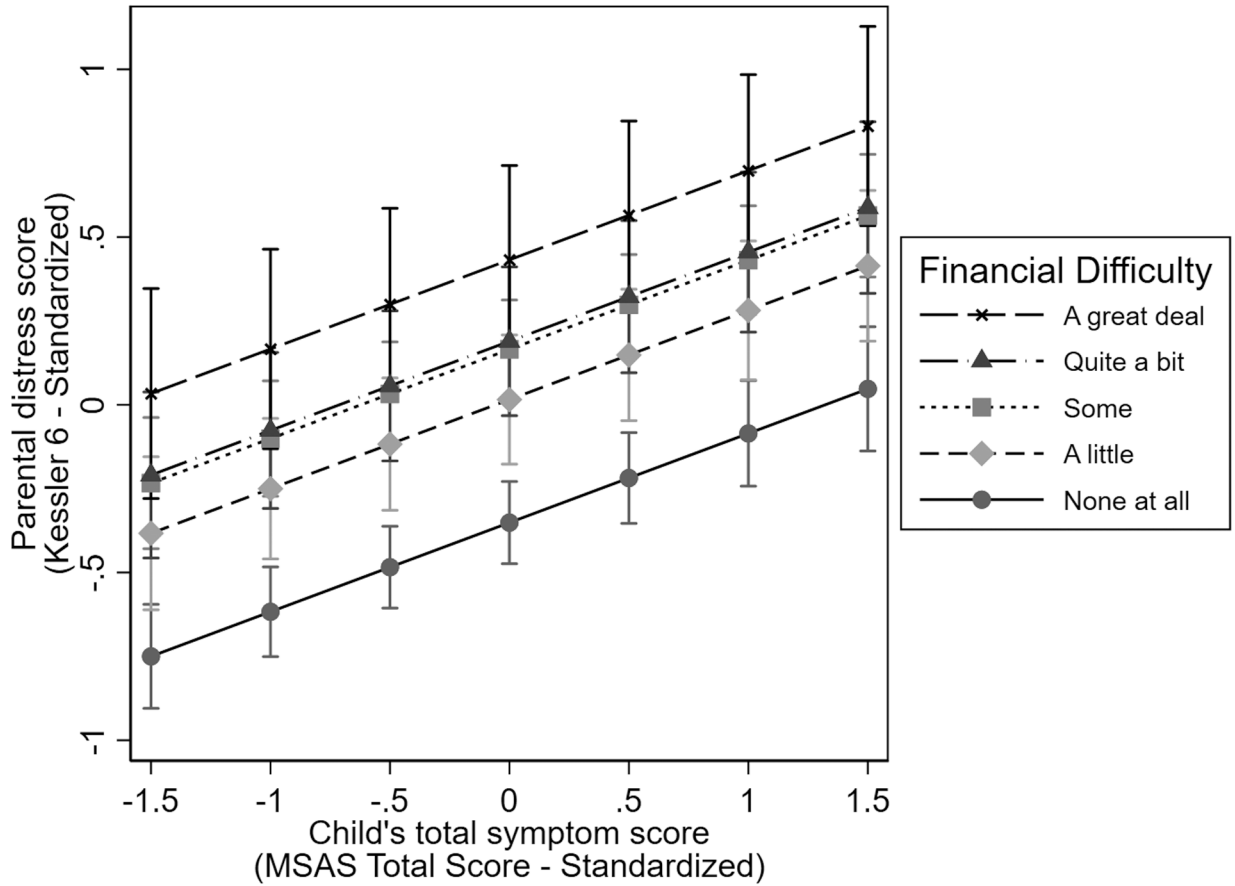


Among those with any financial difficulty...



**Figure 2.** Presence of financial difficulty and characterization of household material hardship





**Figure 3.** Relationship between the parent’s level of distress and the child total symptom score varies by the family’s level of financial difficulty

Note: In this figure, the vertical axis plots the score on the Kessler-6, with 0 representing the mean score and +1 and -1 representing a standard deviation (SD) in the score above and below the mean; the horizontal axis plots the child’s total symptom score in a similar manner; and each of the parallel lines indicate the scores for parents experiencing different degrees of financial difficulty. The fact that these lines slope upward indicates that higher total symptom scores are associated with higher levels of parental psychological distress; and the fact that these lines are separated vertically indicates that increasing levels of financial distress are associated with increasing levels of psychological distress. Combined, the parent of a child with the lowest level of symptom score and in a family with no financial difficulty is predicted to have a level of psychological distress that is 1.6 SD less than a parent of a child with the highest level of symptom score and in a family with a great deal of financial difficulty.

**Table 1.**

Parent psychological distress scores (Kessler-6) and family financial difficulty scores by parent characteristics

Parents' Characteristics (n = 601)		No. (%)	Kessler-6 Score		Financial Difficulty	
			Mean (SD)	P-value	M (SD)	P-value
Parent type	Mother	476 (79.2)	7.7 (5.1)	0.756	1.6 (1.4)	0.229
	Father	125 (20.8)	7.5 (5.0)		1.4 (1.4)	
Age	Years, Mean (standard deviation; SD)	37.9 (9.5)		0.169 <sup>b</sup>		0.119 <sup>b</sup>
	Missing	1				
Race	White	459 (76.5)	7.7 (5.0)	0.934	1.5 (1.3)	0.024
	Black	52 (8.7)	8.0 (5.6)		2.0 (1.6)	
	Asian	29 (4.8)	7.3 (5.7)		1.3 (1.4)	
	American Indian	21 (3.5)	8.3 (5.7)		2.2 (1.1)	
	Other	26 (4.3)	8.1 (5.9)		1.7 (1.6)	
	Prefer not to answer/missing <sup>a</sup>	14 (2.3)	5.0 (0.0)		1.4 (1.6)	
Ethnicity	Non-Hispanic	520 (86.5)	7.6 (5.1)	0.718	1.5 (1.3)	0.052
	Hispanic	71 (11.8)	8.1 (5.5)		1.9 (1.5)	
	Missing <sup>a</sup>	10 (1.7)	8.3 (4.7)		1.3 (1.3)	
Highest Education Level						
Completed	High school/General Educational Diploma	88 (14.6)	7.5 (5.4)	0.842	2.3 (1.4)	<0.001
	Trade/technical/vocational/some college	234 (38.9)	7.6 (5.3)		1.6 (1.3)	
	College/graduate school	276 (45.9)	7.8 (4.8)		1.2 (1.2)	
	Preferred not to answer <sup>a</sup>	3 (0.5)	10.0 (6.6)		2.5 (2.1)	
Relationship Status	Married/partnered	458 (76.2)	7.6 (5.1)	0.122	1.3 (1.3)	<0.001
	Separated/divorced/widowed	53 (8.8)	6.9 (4.5)		2.3 (1.2)	
	Single	76 (12.7)	8.8 (5.6)		2.4 (1.3)	
	Prefer not to answer/other/missing <sup>a</sup>	14 (2.3)	6.7 (5.5)		1.7 (1.4)	
Number of Other Children	0	119 (22.4)	7.6 (5.3)	0.582	1.2 (1.3)	<0.001
	1 to 4	379 (71.2)	7.5 (5.0)		1.6 (1.4)	
	5 or more	32 (6.0)	8.3 (5.8)		2.5 (1.5)	
	Missing <sup>a</sup>	2 (0.4)	11.5 (3.5)		1.0 (1.4)	
Employment Status	Full time	213 (35.4)	7.5 (5.2)	0.405	1.3 (1.2)	<0.001
	Part time	60 (10.0)	7.2 (4.4)		1.5 (1.4)	
	Not employed/Looking for employment	7 (1.2)	7.9 (4.9)		1.6 (1.5)	
	Not employed/Not looking for employment	111 (18.5)	7.4 (5.1)		1.9 (1.4)	
	Homemaker	113 (18.8)	7.6 (5.0)		1.4 (1.3)	
	On leave for child's illness	91 (15.1)	8.8 (5.7)		1.8 (1.5)	
	Preferred not to answer <sup>a</sup>	6 (1.0)	6.7 (2.3)		2.0 (1.2)	

<sup>a</sup>For statistical testing purposes, the "prefer not to answer (etc.)" cells were omitted.

<sup>b</sup>These statistical test regarding the association of increasing age with the scores.

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**Table 2.**

Parent psychological distress scores (Kessler-6) and family financial difficulty scores by patient characteristics

Patients' Characteristics (n = 532)		No. (%)	Kessler-6 Score		Financial Difficulty	
			Mean (SD)	P-value	M (SD)	P-value
Age	<1 month	21 (4.0)	6.4 (3.4)		1.0 (1.1)	
	1–11 months	127 (23.9)	8.3 (5.2)		1.7 (1.4)	
	1–9 years	194 (36.5)	8.0 (5.3)	0.109	1.6 (1.4)	0.099
	10–17 years	156 (29.3)	7.0 (4.7)		1.5 (1.3)	
	18–28 years	34 (6.4)	7.7 (5.5)		1.7 (1.4)	
Sex	Female	247 (46.6)	7.2 (4.7)		1.3 (1.3)	
	Male	283 (53.2)	7.9 (5.5)	0.129	1.8 (1.4)	<0.001
	Prefer not to answer <sup>a</sup>	1 (0.2)	2.0 (0.0)		2.0 (0.0)	
Race	White	380 (71.6)	7.5 (4.9)		1.5 (1.3)	
	Black	67 (12.6)	7.7 (5.4)		1.5 (1.4)	
	Asian	25 (4.7)	7.8 (5.5)	0.995	2.0 (1.6)	0.016
	American Indian	17 (3.2)	7.9 (6.1)		2.3 (1.0)	
	Other	35 (6.6)	7.5 (5.6)		1.7 (1.5)	
	Prefer not to answer/missing <sup>a</sup>	8 (1.3)	8.0 (8.4)		1.7 (1.9)	
Ethnicity	Non-Hispanic	445 (83.7)	8.3 (5.4)		1.5 (1.4)	
	Hispanic	77 (14.5)	7.6 (5.0)	0.447	1.9 (1.4)	0.036
	Prefer not to answer/missing <sup>a</sup>	10 (1.9)	5.0 (5.0)		1.4 (1.0)	
Complex Chronic Condition	Cardiovascular	322 (60.5)	7.6 (5.1)	0.470	1.6 (1.4)	0.358
	Respiratory	215 (40.4)	7.7 (5.2)	0.978	1.7 (1.3)	0.035
	Congenital	227 (42.7)	7.8 (5.2)	0.603	1.5 (1.4)	0.834
	Neuromuscular	306 (57.5)	7.7 (5.2)	0.807	1.6 (1.4)	0.250
	Metabolic	267 (50.2)	8.1 (5.2)	0.038	1.6 (1.3)	0.236
	Malignancy	152 (28.6)	7.8 (4.9)	0.708	1.5 (1.3)	0.827
	Renal	220 (41.4)	7.8 (5.1)	0.623	1.6 (1.4)	0.089
	Gastrointestinal	376 (70.7)	7.8 (5.1)	0.292	1.6 (1.4)	0.032
	Hematologic	180 (33.8)	7.9 (5.0)	0.597	1.6 (1.3)	0.171
	Neonatal	124 (23.3)	7.9 (5.0)	0.584	1.9 (1.3)	<0.001
	Technology Dependent	459 (86.3)	7.7 (5.1)	0.404	1.6 (1.4)	<0.001
	Transplant	72 (13.5)	8.1 (5.2)	0.443	1.4 (1.3)	0.567

<sup>a</sup>For statistical testing purposes, the “prefer not to answer (etc.)” cells were omitted.

**Table 3.**

Parent psychological distress scores (Kessler-6) across levels of household income, financial difficulty, and household material hardship (HMH) categories

		N (%)	Kessler-6 Score	
			Mean (SD)	P-value
Household income (unadjusted)	\$10,000	34 (5.7 %)	7.9 (6.3)	0.042
	\$10,001 to \$20,000	45 (7.5%)	7.6 (6.2)	
	\$20,001 to \$40,000	82 (13.6%)	8.4 (4.8)	
	\$40,001 to \$70,000	137 (22.8%)	8.5 (4.9)	
	\$70,001 to \$100,000	93 (15.5%)	7.3 (5.5)	
	\$100,001 to \$150,000	91 (15.1%)	7.4 (4.4)	
	>\$150,000	60 (10%)	6.9 (4.7)	
	Preferred not to answer/missing <sup>b</sup>	59 (9.8 %)	6.4 (4.5)	
Household income (adjusted for household size of 3 persons <sup>a</sup> )	\$10,000	24 (4.0%)	8.5 (6.0)	0.202
	\$10,001 to \$17,500	49 (8.2%)	6.9 (6.0)	
	\$17,501 to \$36,793	87 (14.5%)	8.4 (5.3)	
	\$36,794 to \$67,500	156 (26.0%)	8.1 (4.9)	
	\$67,501 to \$90,033	89 (14.8%)	7.6 (5.3)	
	\$90,034 to \$150,000	105 (17.5%)	7.6 (4.7)	
	>\$150,000	27 (4.9%)	6.6 (5.0)	
	Preferred not to answer/missing <sup>b</sup>	64 (10.7%)	6.6 (4.6)	
Financial Difficulty	A great deal of difficulty	65 (10.8%)	9.9 (6.1)	<0.001
	Quite a bit of difficulty	74 (12.3%)	8.7 (5.4)	
	Some difficulty	143 (23.8%)	8.6 (4.5)	
	A little difficulty	104 (17.3%)	7.8 (5.1)	
	No difficulty at all	186 (31.0%)	5.8 (4.2)	
	Preferred not to answer/missing <sup>b</sup>	29 (4.8%)	7.4 (5.7)	
HMH in the last 6 months	Lived with other people	61 (10.2 %)	9.4 (5.9)	0.006
	Rent wasn't paid on time	133 (22.2%)	9.2 (5.6)	<0.001
	Threatened to shut off utilities	118 (19.7%)	8.9 (5.4)	0.004
	Home was not heated/cooled	28 (4.7%)	12.6 (6.3)	<0.001
	Possibility of food running out	134 (22.4%)	9.1 (5.3)	0.002
	Weren't able to purchase food	103 (17.2%)	9.3 (5.6)	0.001
HMH Composite Score <sup>c</sup>	0	351 (60.9%)	6.9 (4.9)	<0.001
	1	76 (13.2%)	8.6 (4.6)	
	2	48 (8.3%)	7.5 (4.4)	
	3	44 (7.6%)	8.0 (4.9)	
	4	22 (3.8%)	7.3 (4.5)	
	5	18 (3.1%)	10.1 (6.3)	
	6	7 (1.2%)	15.4 (5.1)	
	7	7 (1.2%)	13.4 (3.7)	

	N (%)	Kessler-6 Score	
		Mean (SD)	P-value
8	3 (0.5%)	9.7 (8.5)	

<sup>a</sup> Adjustment for household size was calculated for each participating family by taking the midpoint value of their income category range and dividing by the square root of the number of persons in the household.

<sup>b</sup> For statistical testing purposes, the “prefer not to answer/missing” cells were omitted.

<sup>c</sup> HMH Composite Scores were comprised of the sum of HMH questions regarding financial difficulty covering housing, utility, and food costs, where higher numbers indicate greater number and severity of difficulties.

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