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Screening for caregiver psychosocial risk in children with medical complexity: a cross-sectional study

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ABSTRACT

Objective To quantify psychosocial risk in family caregivers of children with medical complexity using the Psychosocial Assessment Tool (PAT) and to investigate potential contributing sociodemographic factors.

Design Cross-sectional study.

Setting Family caregivers completed questionnaires during long-term ventilation and complex care clinic visits at The Hospital for Sick Children, Toronto, Ontario, Canada.

Patients A total of 136 family caregivers of children with medical complexity completed the PAT questionnaires from 30 June 2017 through 23 August 2017.

Main outcome measures Mean PAT scores in family caregivers of children with medical complexity. Caregivers were stratified as 'Universal' low risk, 'Targeted' intermediate risk or 'Clinical' high risk. The effect of sociodemographic variables on overall PAT scores was also examined using multiple linear regression analysis. Comparisons with previous paediatric studies were made using T-test statistics.

Results 136 (103 females (76%)) family caregivers completed the study. Mean PAT score was 1.17 (SD=0.74), indicative of 'Targeted' intermediate risk. Sixty-one (45%) caregivers were classified as Universal risk, 60 (44%) as Targeted risk and 15 (11%) as Clinical risk. Multiple linear regression analysis revealed an overall significant model (p=0.04); however, no particular sociodemographic factor was a significant predictor of total PAT scores.

Conclusion Family caregivers of children with medical complexity report PAT scores among the highest of all previously studied paediatric populations. These caregivers experience significant psychosocial risk, demonstrated by larger proportions of caregivers in the highest-risk Clinical category.

What is known about the subject?

- Children with medical complexity are a growing population with disproportionate uses of healthcare resources.
- Caregivers of these children experience unique challenges including maintenance of technology at home, poor care coordination with multiple health providers and prolonged hospitalisations.
- Despite children with medical complexity accounting for 43% of all paediatric deaths in the USA, caregiver psychosocial risk in this population has not been quantitatively studied.

What this study adds?

- The prevalence of psychosocial risk in families caring for children with medical complexity are among the highest of all previously studied paediatric populations.
- Being able to quantify a caregiver's level of risk will ensure appropriate social support and resource allocation to at-risk families.

INTRODUCTION

Children with medical complexity (CMC)[1 2] are defined by medical fragility, dependence on technology at home and substantial care needs.[3] An estimated 0.4%–0.7% of children in the USA and Canada meet the definition for CMC; however, their healthcare costs account for approximately one-third of all child health spending.[4 5] Family caregivers (FCs) of CMC are an essential population of caregivers with unique challenges. These include prolonged hospitalisations,[6] poor care coordination[7] and the expectation of always being 'on call' where short delays in recognition and response to emergency situations can have deleterious consequences.[8] As many of these conditions are diagnosed in infancy, FCs may be tasked with sustaining caregiver demands for decades as both parents and healthcare providers.[9] Altogether, these enormous challenges result in extensive caregiver stress with negative physical and emotional consequences, which may then seriously impact their ability to care for their child.[10–14]

Despite CMC in the USA accounting for 43% of paediatric deaths, 49% of paediatric hospitalisation days and 73%–92% of assistive health technology (eg, tracheostomy, gastrostomy tube) use in children,[15 16] existing literature on psychosocial risk of caregivers of CMC is limited primarily to qualitative studies.[1 17–19]

Identified risk factors include the child's dependence on assistive technology,[20] presence of other children at home,[20] limited financial resources[21] and poor social supports.[12 13] However, there remains a need to quantitatively measure the psychosocial risk of FCs of CMC similar to previous studies in children with oncological, renal, gastrointestinal and cardiac diseases.[22–24] As with these studies, systematic screening of FCs of CMC may facilitate early intervention and appropriate allocation of social support resources to those at highest need. Enhancing the care of CMC remains an urgent priority.[5 25] Our aim was to quantify psychosocial risk in FCs of CMC and investigate sociodemographic factors that may identify families at greatest risk.

METHODS

Study design and setting

This single-centre, cross-sectional study was conducted at the Hospital for Sick Children (SickKids), Toronto, Canada. Study participants were recruited from 30 June 2017 to 23 August 2017. This study was written in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology statement (online supplementary appendix 1).

Patient and public involvement

Patients were not involved in the design and/or conduct of this study.

Study participants

The inclusion criteria was as follows: (1) FC of a child aged <18 years satisfying the Provincial Council for Maternal and Child Health Standard Operational Definition for CMC who are medically fragile and/or technology dependent[3] and (2) the children were followed in the long-term ventilation and/or complex care programmes. The exclusion criteria was failure to consent for the study by the parent or authorised caregiver and caregivers unable to complete the questionnaire in English.

Study measures

Demographic and socioeconomic review

Health records were retrospectively reviewed for study participants' children capturing their age, gender, primary medical diagnosis (adapted from Wallis *et al*[26]), date of diagnosis, medications, medical technologies used at home, community supports and healthcare utilisation (ie, length of hospital admission in the past year). Community supports included the number of nursing and personal support worker hours per week, respite admissions per year and other homecare and/or income supports.

The PAT

The Psychosocial Assessment Tool (PAT) is a brief parent-reported screening tool for measuring psychosocial risk in caregivers of paediatric patients.[27] Originally developed in paediatric oncology, the modified PAT questionnaire (PATrev) has been used to study other paediatric populations.[24 28–31] The 15-item PAT questionnaire is completed in 5–10 min and assesses seven subscales: family structure/resources, social support, patient/child problems, sibling problems, caregiver problems, caregiver stress reactions and family beliefs. For this study, prompts related to a cancer diagnosis were removed from questions 9 and 15 of the PAT after consultation with the original PAT developers. The complete PAT is shown in online supplementary appendix 2.

Study procedures

Eligible caregivers were approached during scheduled clinic visits by the attending physician. Those who expressed interest were then invited to meet with the Research Assistant to obtain further details and provide written consent. All PAT questionnaires were filled out on paper in-person by caregivers themselves. PAT questionnaires were scored within 24 hours of completion. Final scores for the seven subscales were calculated via the summation of the risk factors endorsed by FC, divided by the total number of risk items for the sub-scale. The total PAT score was then derived from the sum of all seven subscale scores. Based on The Pediatric Psychosocial Preventative Health Model (PPPHM), the total PAT score stratifies FCs into three levels of psychosocial risk: low-risk 'Universal' families with normal transient levels of stress (total score <1.0), intermediate-risk 'Targeted' families with acute or elevated levels of stress (total score between 1.0 and 1.9) and high-risk 'Clinical' families with severe stress (total score ≥2.0).[24 32]

Statistical analysis

Clinical and demographic characteristics of participating children and FCs were summarised with descriptive statistics. For the primary analysis, the prevalence of psychosocial risk in each of the three risk categories was calculated as a percentage of all FCs using the total PAT scores. To compare the PAT scores from caregivers of ventilated children with those of non-ventilated children, a Mann-Whitney Wilcoxon test was conducted. Previous studies using the PAT score were found by conducting a search of online databases Ovid MEDLINE and Web of Science from inception to 28 April 2020 using keywords 'Psychosocial Assessment Tool', 'caregiver' and 'pediatrics'. Included studies measured the psychosocial risk in caregivers of specific paediatric populations using the PAT. Independent t-tests were then used to compare the mean PAT scores between each study and the current study; p values were corrected using the Šidák correction for multiple comparisons.

For the secondary analysis, linear regression was used to explore predictors of psychosocial risk in caregivers at the time of their clinic visit; the variables tested were not scored within the PAT and included sex of both the child and caregiver, child age, number of caregivers at home, employment status, annual family income, hours/week of paid homecare support, CMC's hospital

admission days in the previous year and the number of medical technologies. Variables with p<0.2 at the bivariate level were entered into a multiple regression analysis; multicollinearity was checked using the variance inflation factor. A backward selection method was used to eliminate variables that had least significance and did not impact the estimates of other variables in the model by 10%. Statistical analysis was performed using SAS V.9.3 (SAS Institute, Cary, North Carolina, USA). The level of significance was set at p<0.05 for all analyses.

RESULTS

One hundred seventy-nine families were eligible for recruitment. Of these families, 2 were not approached at the request of the clinicians, while another 13 were missed due to scheduling conflicts. The remaining 164 families were approached for participation. Twenty-three families (14%) declined, citing lack of interest and/or time as primary reasons. Five caregivers (3%) requested to take home the questionnaires but did not return them. Overall, 136 (83%) of the 164 caregivers completed the questionnaires. These questionnaires contained no missing details.

The demographic information for FCs and CMC is presented in tables 1 and 2. FCs had a mean age of 42 years (SD 8.5 years). Seventy-six per cent were females (n=103), 23% were males (n=32) and one FC did not report their sex. Seventy-four FCs (54%) reported some degree of financial difficulty at home. Of the 136 children, the mean age was 9 years (SD 5.3 years). Seventy-eight CMC (57%) received long-term mechanical ventilation (invasive or non-invasive) at home.

Prevalence of psychosocial risk

Total PAT scores ranged from 0.00 to 3.92 (mean=1.17, median=1.13, SD=0.74). The most endorsed PAT items by FCs of CMC were child problems, caregiver problems and caregiver stress reactions. The least reported items were social support and sibling problems. Table 3 contains the final scores and subscale scores for all included FCs.

Of all 136 FCs, 45% (n=61) fell into the Universal low-risk category, 44% (n=60) fell into the Targeted intermediate-risk category and 11% (n=15) fell into the Clinical high-risk category. Caregivers of ventilated children reported a mean PAT score of 1.29 (SD=0.83) and FCs of non-ventilated children reported a mean PAT score of 1.00 (SD=0.57). This difference was not significant (p=0.06).

Our search identified 28 previous studies that used the PAT in children (table 4). In comparison to these studies, FCs of our CMC population have the third highest overall PAT scores. Our mean PAT score is significantly higher than 14 of the 26 studies from which we were able to perform our analysis (p<0.05).

Table 1 Demographic characteristics of the 136 family caregivers included in this study

Gender	n=136
Female	103 (76%)
Male	32 (23%)
Did not disclose	1 (1%)
Age (years)	
20–29	6 (4%)
30–39	46 (34%)
40–49	56 (41%)
50–59	19 (14%)
60–69	3 (2%)
70–79	1 (1%)
Did not disclose	5 (4%)
Ethnicity (mother)	
European	57 (42%)
Asian	50 (37%)
Caribbean/Indian-Caribbean	11 (8%)
Other	11 (8%)
African	7 (5%)
Ethnicity (father)	
European	55 (40%)
Asian	46 (34%)
Other	15 (11%)
Caribbean/Indian-Caribbean	12 (9%)
African	8 (6%)
Marital status	
Single or separated	31 (23%)
Married/Partnered	104 (76%)
Did not disclose	1 (1%)
Education	
Started high school	7 (5%)
Graduated high school	19 (14%)
Some tertiary study	23 (17%)
Finished college or trade school	68 (50%)
Finished Master's or Doctoral programme	17 (13%)
Did not disclose	2 (1%)
Relation to child	
Biological parent	126 (93%)
Grandparent	4 (3%)
Foster parent	3 (2%)
Aunt/Uncle/Other relative	2 (1%)
Step parent	1 (1%)
Role with child	
Primary (daily) caregiver	128 (94%)
Supporting/Back-up caregiver	5 (4%)

Continued

Table 1 Continued

Occasional caregiver	2 (1%)
Other	1 (1%)
Caregivers at home	
1	17 (12%)
2	95 (70%)
≥3	24 (18%)
After-tax income (US$)	
<30 000	27 (20%)
30 000–79 999	49 (36%)
80 000–149 999	29 (21%)
≥150 000	11 (8%)
Did not disclose	20 (15%)
Employment status	
Full-time	54 (40%)
Part-time	13 (9%)
Unemployed	42 (31%)
Did not disclose	27 (20%)
Financial difficulty	
No problems	62 (46%)
Some problems	49 (36%)
Difficulty meeting family needs	25 (18%)

Predictors of psychosocial risk

The initial univariate analysis revealed FC sex (p=0.03), length of hospitalisations (p=0.04), FC employment status (p=0.04), number of medical technologies (p=0.08) and hours of paid homecare support (p=0.1) to be likely predictors of PAT scores (p<0.2). These variables were then entered into the multiple regression analysis. The results indicate an overall significant model; however, none of FC sex (p=0.2), length of hospitalisations (p=0.3), FC employment status (p=0.07), number of medical technologies (p=0.8) or paid homecare support (p=0.4) contributed significantly to the model (p>0.05). Results of the regression analysis are displayed in table 5. Therefore, these sociodemographic factors were not significant predictors of caregivers' overall PAT scores.

DISCUSSION

We found that FCs of CMC suffer significant psychosocial risk demonstrated by an overall PAT score of 1.17 and more than 1 in 10 caregivers scoring in the high-risk category. Our findings also suggest that chronic ventilation at home may add another layer of stress to caregivers. Additionally, the included sociodemographic factors were not found to be significant predictors of the total PAT score.

Compared with previous studies in children,[22–24 27 29–31 33–53] the distribution of PAT scores for FCs of CMC is substantially weighted towards the higher risk categories (45% Universal, 44% Targeted, 11% Clinical).

Table 2 Demographic and disease characteristics of the 136 children with medical complexity at the time of their clinic visit

Gender	n=136
Male	86 (63%)
Female	50 (37%)
Age (years)	
0–4	34 (25%)
5–9	33 (24%)
10–14	39 (29%)
15–18	30 (22%)
Primary diagnosis	
Central nervous system (n=38%–28%)	
Congenital central hypoventilation syndrome	9 (7%)
Spinal injury	6 (4%)
Birth injury/cerebral palsy	5 (4%)
Acquired central hypoventilation syndrome	3 (2%)
Other central causes	15 (11%)
Musculoskeletal (n=82%–61%)	
Duchenne's muscular dystrophy	19 (14%)
Other dystrophy	18 (13%)
Spinal muscular atrophy	13 (10%)
Congenital myopathy	8 (6%)
Other myopathy	8 (6%)
Mucopolysaccharidoses	3 (2%)
Other musculoskeletal	13 (10%)
Respiratory (n=10%–7%)	
Upper airway obstruction	4 (3%)
Chronic lung disease	3 (2%)
Airway malacia	1 (1%)
Other respiratory	2 (1%)
Unclassified (n=6%–4%)	
Days in hospital in the past 12 months	
0–1	81 (59%)
2–10	34 (26%)
>10	21 (15%)
Paid homecare support* (hours/week)	
0	73 (54%)
1–19	14 (10%)
20–49	27 (20%)
>50	22 (16%)
Number of technologies	
0–1	37 (27%)
2–4	57 (42%)
≥5	42 (31%)
Technology	

Continued

Table 2 Continued	
Oxygen saturation monitor	79 (58%)
Wheelchair	79 (58%)
BiPAP (nocturnal)	52 (38.%)
Cough assist	51 (38%)
Suction	49 (36%)
Gastrostomy tube	37 (27%)
Supplemental oxygen (nocturnal/naps)	19 (14%)
Trach/Vent (nocturnal/naps)	18 (13%)
Gastrojejunostomy tube	17 (13%)
Trach/Vent (24 hours/day)	9 (7%)
Trach only	6 (4%)
Supplemental oxygen (24 hours)	3 (2%)
Ventriculoperitoneal shunt	3 (2%)
CPAP	2 (1%)
Lifting device	2 (1%)
Sip ventilation	1 (1%)
Port-a-Cath	1 (1%)

*Homecare supports included the number of nursing and personal support worker hours per week.
BiPAP, Bilevel positive airway pressure; CPAP, continuous positive airway pressure; Trach/Vent, tracheostomy and ventilation.

The first paediatric studies using PAT questionnaires in children with cancer categorised 50%–72% of FCs as Universal risk, 24%–41% as Targeted risk and 4%–9% as Clinical risk.[22 27 34 35] These scores are notably lower than those seen in our study. Only two previous paediatric studies on sickle cell disease[29 36] and one on stem cell transplant recipients[43] reported even higher Clinical-risk families. In the CMC population, the higher proportion of families in the Clinical group may be attributed to intense stressors ranging from acute care admissions to clinic appointments, prolonged hospitalisations, ordering of medical equipment for their child, uncertainty of life expectancy and time spent by caregivers advocating for resources.[13 19 54] These stressors often have emotional and financial implications such as marriage breakdowns and employment changes.[55 56] Some caregivers are even diagnosed with post-traumatic stress disorder.[9]

Higher PAT scores among FCs of CMC may also be explained by the chronicity of their healthcare needs. This is unique from other populations such as children with oncologic conditions where there is a relatively acute stage of intense stress.[57] Families of CMC are tasked with these overwhelming duties for years leading to persistently increased caregiver psychosocial risk. Interestingly, FCs of CMC also have higher reported PAT scores than other chronic paediatric diseases such as children with sickle cell disease, congenital heart disease and renal failure. This may be attributed to the use of assistive technologies at home that has been previously identified as a risk factor to a caregiver's psychosocial risk.[20]

In our study, we found that families caring for CMC receiving long-term mechanical ventilation at home may be at an even greater psychosocial risk. These caregivers reported higher PAT scores than those of children who were not ventilated; however, this difference was not significant (p=0.06). Previous studies have described the additional challenges experienced by parents of ventilated children.[12 13 19 21 54] These include more provider visits for ventilator care and constant anxiety about ventilator malfunction.[54] Caregivers of children on ventilator support also report offensive reactions from their everyday community devaluing their child's life as a 'life not worth maintaining'.[21] This leads to social avoidance and further isolates these families. Thus, psychosocial risk in this subgroup of FCs needs to be further studied as these caregivers may require additional social assistance compared with caregivers of CMC using other assistive technologies.

We did not observe a significant association between caregivers' sociodemographic factors and their overall PAT scores. There are limited paediatric studies that have examined this relationship.[23 37 39 42] For example, Hearps *et al*[23] investigated caregivers of children with congenital heart disease and found only lower parental education attainment to be a significant predictor of higher PAT scores. Parental education was also deemed significant in two other studies of children with cystic fibrosis[39] and cancer.[37] To the best of our knowledge, this relationship

Table 3 Descriptive statistics for PAT total scores and subscale scores (n=136)

PAT scale (items)	Scale range	Mean	SD	Range
Total	0–7	1.17	0.74	0–3.92
Family structure/resources(education, marital status, 1, 3, 6, 7)	0–7	0.17	0.16	0–0.71
Social support (2a-d)	0–4	0.09	0.22	0–1.00
Child problems (9a-d, k-u, w)	0–16	0.29	0.20	0–0.88
Sibling problems(10a-d, g-u, w)	0–20	0.08	0.13	0–0.69
Caregiver problems(11a-e, g-j, l)	0–10	0.22	0.19	0–0.90
Caregiver stress reactions(12a-e)	0–5	0.20	0.29	0–1.00
Family beliefs(14a-l)	0–12	0.12	0.11	0–0.67

PAT, Psychosocial Assessment Tool.

Table 4 Comparison of family caregivers' PAT scores from other paediatric populations with this study

Study	Population	Universal n (%)	Targeted n (%)	Clinical n (%)	Mean PAT score	95% CI of the difference	P value
Verma *et al (this study)*, n=136	Children with medical complexity	61 (45%)	60 (44%)	15 (11%)	1.17		
Reader *et al*, n=136[36]	Sickle cell disease	63 (46%)	54 (40%)	19 (14%)	1.15	0.16 to 0.20	0.8
Sharkey *et al*, n=262[37]	Cancer	NR	NR	NR	1.02	0.00 to 0.30	0.05
Tsumura *et al*, n=117[38]	Cancer	NR	NR	NR	1.45	−0.48 to 0.0.8	0.006
Filigno *et al*, n=154[39]	Cystic fibrosis	80 (52%)	63 (41%)	11 (7%)	1.00	0.00 to 0.34	0.05
Kapa *et al*, n=217[40]	Craniofacial	NR	NR	NR	0.91	0.10 to 0.42	0.001
Law *et al*, n=235[41]	Headache	134 (57%)	82 (35%)	19 (8%)	0.99	0.04 to 0.33	0.02
Rocque *et al*, n=40[42]	Brain tumour	24 (60%)	15 (38%)	1 (2%)	0.89	0.03 to 0.52	0.03
Pai *et al*, n=140[43]	Stem cell transplant	76 (54%)	42 (30%)	22 (16%)	1.14	−0.15 to 0.21	0.7
Schulte *et al*, n=95[44]	Cancer	NR	NR	NR	0.84	0.14 to 0.52	<0.001
Crerand *et al*, n=217[45]	Craniofacial	130 (60%)	70 (32%)	17 (8%)	0.91	0.11 to 0.41	<0.001
Ernst *et al* n=197[46]	Disorders of sexual development	130 (66%)	55 (28%)	12 (6%)	0.86	0.16 to 0.46	<0.001
Kazak *et al*, n=394[47]	Cancer	246 (62%)	106 (27%)	42 (11%)	0.97	0.06 to 0.34	0.005
Cousino *et al*, n=56[48]	Heart transplant	33 (59%)	17 (30%)	6 (11%)	0.96	0.02 to 0.44	0.08
Phan *et al*, n=100[31]	Obesity	7 (27%)	17 (65%)	2 (8%)	1.20	−0.20 to 0.14	0.7
Woods and Ostrowski-Delahanty n=127[49]	Headache	NR	NR	NR	1.12	−0.12 to 0.22	0.6
Clapin *et al*, n=49[50]	Type 1 diabetes	NR	NR	NR	1.00	0.07 to 0.41	0.2
Pierce *et al*, n=67[51]	Cancer	42 (63%)	21 (31%)	4 (6%)	0.90	0.06 to 0.48	0.01
McCarthy *et al*, n=89[52]	Cancer	51 (57%)	34 (38%)	4 (5%)	1.00	−0.01 to 0.35	0.07
Sint Nicolaas *et al*, n=117[53]	Cancer	77 (66%)	34 (29%)	6 (5%)	0.80	0.20 to 0.54	<0.001
Pai *et al*, n=42[30]	Inflammatory bowel disease	27 (64%)	15 (36%)	0 (0%)	0.77	0.21 to 0.59	<0.001
Barrera *et al*, n=67[22]	Cancer	40 (60%)	21 (31%)	6 (9%)	NR		

Continued

Table 4 Continued

Study	Population	Universal n (%)	Targeted n (%)	Clinical n (%)	Mean PAT score	95% CI of the difference	P value
Hearps *et al*, n=39[23]	Congenital heart disease	24 (62%)	14 (36%)	1 (2%)	0.81	0.14 to 0.58	0.001
Karlson *et al*, n=219[29]	Sickle cell disease	109 (50%)	80 (36%)	30 (14%)	1.12	−0.11 to 0.21	0.5
Pai *et al*, n=45[24]	Kidney transplant	NR	NR	NR	0.98	−0.06 to 0.44	0.1
Kazak *et al*, n=50[33]	Cancer	36 (72%)	12 (24%)	2 (4%)	0.76	0.20 to 0.62	<0.001
McCarthy *et al*, n=220[34]	Cancer	147 (67%)	52 (24%)	21 (9%)	0.93	0.21 to 0.51	<0.001
Alderfer *et al*, n=102[35]	Cancer	51 (50%)	42 (41%)	9 (9%)	NR		
Pai *et al*, n=205[27]	Cancer	122 (59%)	65 (32%)	18 (9%)	1.02	−0.01 to 0.31	0.07

P values were obtained by performing independent t-tests to compare each study with the current study; p values were corrected using the Šidák correction for multiple comparisons.
.NR, not reported; PAT, Psychosocial Assessment Tool.

has not been previously examined in CMC using the PAT. In our model, we did not include the caregiver's level of education as this variable is inherently included within our PAT questionnaire. Our results are in accordance with another recent study by Rocque *et al*[42] that investigated children with brain tumours. As in our study, demographic factors were not found to be significantly predictive of PAT scores. Since our overall model was determined to be significant, sociodemographic factors have some contribution to overall PAT scores. However, we emphasise to clinicians caring for CMC that no one particular demographic characteristic can be used to identify families at greatest psychosocial risk. Altogether, this further underscores the importance of an objective screening measure to identify these caregivers, such as the PAT.

Our study has some notable limitations. First, as a single-centre study, our findings may not be generalisable to all institutions in the USA and Canada. Second, despite the high level of caregiver enrolment in this study (83%), the level of psychosocial risk in those who did not participate remains unknown and introduces the risk for participation bias. It may be possible that families unable to attend their scheduled clinic visit or those with limited English proficiency may be experiencing more stress than the caregivers sampled. Third, as the majority of

Table 5 Summary of multiple regression analysis of caregivers' sociodemographic factors on total PAT scores

Variable	B coefficient	SE	95% CI	P value
Child's hospitalisation days in previous year (0–1 days)	−0.30	0.19	−0.68 to 0.08	0.1
Child's hospitalisation days in previous year (2–10 days)	−0.28	0.21	−0.69 to 0.13	0.2
Child's hospitalisation days in previous year (>10 days)	Reference	–	–	–
Paid homecare support (0 hours/week)	−0.37	0.22	−0.81 to 0.07	0.1
Paid homecare support (1–19 hours/week)	−0.30	0.26	−0.83 to 0.22	0.3
Paid homecare support (20–49 hours/week)	−0.23	0.22	−0.65 to 0.20	0.3
Paid homecare support (>50 hours/week)	Reference	–	–	–
Caregiver employment status (full-time)	−0.21	0.17	−0.55 to 0.14	0.2
Caregiver employment status (part-time)	−0.30	0.24	−0.78 to 0.18	0.2
Caregiver employment status (unemployed)	0.16	0.18	−0.20 to 0.52	0.4
Caregiver employment status (did not disclose)	Reference	–	–	–
Caregiver sex	0.19	0.16	−0.12 to 0.50	0.2
Number of medical technologies	−0.01	0.41	−0.09 to 0.07	0.8

PAT, Psychosocial Assessment Tool.

caregivers enrolled in this study were females, our results may not represent the perceptions of male providers. Lastly, the cross-sectional design of our study is a limitation as certain psychosocial stressors may not have been evident for some families at the time of questionnaire completion.

Overall, our results highlight the need for psychosocial risk screening and support services among families of CMC. Caregivers of CMC experience significant psychosocial risk and, therefore, interventions including financial assistance and social support remain an urgent priority for children's hospitals serving this important population of children. The brevity of completing and scoring this questionnaire suggests its feasibility in clinical use. The PAT can effectively screen for risk among families who may be reluctant to verbally report psychosocial difficulties, such as financial problems and mental health concerns. Future research is encouraged to validate the reliability of the PAT as a screening tool for the CMC population in other institutions worldwide as well as its responsiveness to targeted psychosocial risk interventions.

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