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.

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 4 5 Family caregivers (FCs) of CMC are an essential population of caregivers with unique challenges. These include prolonged hospitalisations,6 poor care coordination7 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, gastrosomy tube) use in children,13–16 existing literature on psychosocial risk of caregivers of CMC is limited primarily to qualitative studies.11–19
Identified risk factors include the child’s dependence on assistive technology,20 presence of other children at home,20 limited financial resources21 and poor social supports.1213 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.525 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 dependent3 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 al26), 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.2428–31 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).2432

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
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, the distribution of PAT scores for FCs of CMC is substantially weighted towards the higher risk categories (45% Universal, 44% Targeted, 11% Clinical).
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 disease29 36 and one on stem cell transplant recipients43 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.37 39 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 55 56 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.39 42 43 45 For example, Hearps et al.39 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 fibrosis30 and cancer.37 To the best of our knowledge, this relationship

| 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.

| 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 | 0–7 | 0.17 | 0.16 | 0–0.71 |
| Social support | 0–4 | 0.09 | 0.22 | 0–1.00 |
| Child problems | 0–16 | 0.29 | 0.20 | 0–0.88 |
| Sibling problems | 0–20 | 0.08 | 0.13 | 0–0.69 |
| Caregiver problems | 0–10 | 0.22 | 0.19 | 0–0.90 |
| Caregiver stress reactions | 0–5 | 0.20 | 0.29 | 0–1.00 |
| Family beliefs | 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                               | Sickle cell disease                       | 63 (46%)        | 54 (40%)       | 19 (14%)       | 1.15           | 0.16 to 0.20              | 0.8     |
| Sharkey et al, n=262                              | Cancer                                    | NR              | NR             | NR             | 1.02           | 0.00 to 0.30              | 0.05    |
| Tsuma et al, n=117                                 | Cancer                                    | NR              | NR             | NR             | 1.45           | −0.48 to 0.08             | 0.006   |
| Filigno et al, n=154                               | Cystic fibrosis                           | 80 (52%)        | 63 (41%)       | 11 (7%)        | 1.00           | 0.00 to 0.34              | 0.05    |
| Kapa et al, n=217                                  | Craniofacial                              | NR              | NR             | NR             | 0.91           | 0.10 to 0.42              | 0.001   |
| Law et al, n=235                                   | Headache                                  | 134 (57%)       | 82 (35%)       | 19 (8%)        | 0.99           | 0.04 to 0.33              | 0.02    |
| Rocque et al, n=40                                 | Brain tumour                              | 24 (60%)        | 15 (38%)       | 1 (2%)         | 0.89           | 0.03 to 0.52              | 0.03    |
| Pai et al, n=140                                   | Stem cell transplant                      | 76 (54%)        | 42 (30%)       | 22 (16%)       | 1.14           | −0.15 to 0.21             | 0.7     |
| Schulte et al, n=95                                | Cancer                                    | NR              | NR             | NR             | 0.84           | 0.14 to 0.52              | <0.001  |
| Crerand et al, n=217                               | Craniofacial                              | 130 (60%)       | 70 (32%)       | 17 (8%)        | 0.91           | 0.11 to 0.41              | <0.001  |
| Ernst et al, n=197                                 | Disorders of sexual development           | 130 (66%)       | 55 (28%)       | 12 (6%)        | 0.86           | 0.16 to 0.46              | <0.001  |
| Kazak et al, n=394                                 | Cancer                                    | 246 (62%)       | 106 (27%)      | 42 (11%)       | 0.97           | 0.06 to 0.34              | 0.005   |
| Cousino et al, n=56                                | Heart transplant                          | 33 (59%)        | 17 (30%)       | 6 (11%)        | 0.96           | 0.02 to 0.44              | 0.08    |
| Phan et al, n=100                                  | Obesity                                   | 7 (27%)         | 17 (65%)       | 2 (8%)         | 1.20           | −0.20 to 0.14             | 0.7     |
| Woods and Ostrowski-Delahanty, n=127               | Headache                                  | NR              | NR             | NR             | 1.12           | −0.12 to 0.22             | 0.6     |
| Clapin et al, n=496                                | Type 1 diabetes                           | NR              | NR             | NR             | 1.00           | 0.07 to 0.41              | 0.2     |
| Pierce et al, n=67                                 | Cancer                                    | 42 (63%)        | 21 (31%)       | 4 (6%)         | 0.90           | 0.06 to 0.48              | 0.01    |
| McCarthy et al, n=89                               | Cancer                                    | 51 (57%)        | 34 (38%)       | 4 (5%)         | 1.00           | −0.01 to 0.35             | 0.07    |
| Sint Nicolaas et al, n=117                         | Cancer                                    | 77 (66%)        | 34 (29%)       | 6 (5%)         | 0.80           | 0.20 to 0.54              | <0.001  |
| Pai et al, n=428                                   | Inflammatory bowel disease                | 27 (64%)        | 15 (36%)       | 0 (0%)         | 0.77           | 0.21 to 0.59              | <0.001  |
| Barrera et al, n=67                                | Cancer                                    | 40 (60%)        | 21 (31%)       | 6 (9%)         | NR             |                          |         |

Continued
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

| 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\(^34\)     | 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\(^15\)  | Cancer                     | 51 (50%)        | 42 (41%)       | 9 (9%)         | NR              |                         |         |
| Pai et al, n=205\(^57\)    | 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.

### 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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RV and RA were involved in all stages of the project and co-wrote the initial version of the manuscript. YM, NS, KN, JV, AE and JP were involved in patient recruitment, data collection and manuscript revision phases. RA and JO conceptualised the project and provided oversight as well as manuscript creation and revision. RA accepts full responsibility and should be contacted for all correspondence purposes. All authors agree with all aspects of this manuscript.

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Data are available on reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. Participants’ raw data can be obtained from the corresponding author.

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REFERENCES
1 Himelstein BP, Hilden JM, Boldt AM, et al. Pediatric palliative care. N Engl J Med 2004;350:1752–62.
2 Judson L. Global childhood chronic illness. Nurs Adm Q 2004;28:60–6.
3 Provincial Council for Maternal and Child Health. Pursuing the possible: an action plan for transforming the experiences of children and youth who are medically fragile and/or technology dependent 2013.
4 Cohen E, Berry JG, Camacho X, et al. Patterns and costs of health care use of children with medical complexity. Pediatrics 2012;129:e1463–73.
5 Neff JM, Sharp VL, Muldoon J, et al. Profile of medical charges for children by health status group and severity level in a Washington state health plan. Health Serv Res 2004;39:73–90.
6 Dosa NP, Boeing NM, Ms N, et al. Excess risk of severe acute illness in children with chronic health conditions. Pediatrics 2001;107:499–504.
7 Matlow AG, Wright JG, Zimmerman B, et al. How can the principles of complexity science be applied to improve the coordination of care for complex pediatric patients? Qual Saf Health Care 2006;15:85–8.
8 Dewan T, Cohen E. Children with medical complexity in Canada. Paediatr Child Health 2013;18:518–22.
9 Koch KD, Jones BL. Supporting parent caregivers of children with life-limiting illness. Children 2018;5:85.
10 Keilty K, Cohen E, Spalding K, et al. Sleep disturbance in family caregivers of children who depend on medical technology. Arch Dis Child 2018;103:137–42.
11 Raina P, O’Donnell M, Rosenbaum P, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics 2005;115:e226–30.
12 Kuster PA, Badr LK. Mental health of mothers caring for ventilator-assisted children at home. Issues Ment Health Nurs 2006;27:817–35.
13 Hefner JL, Tsai WC. Ventilator-Dependent children and the health services system. unmet needs and coordination of care. Ann Am Thorac Soc 2013;10:482–9.
14 Cohen E, Horváth-Puho E, Ray JG, et al. Association between the birth of an infant with major congenital anomalies and subsequent risk of mortality in their mothers. JAMA 2016;316:2515–24.
15 Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics 2010;126:647–55.
16 Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children’s hospitals: a longitudinal, multi-institutional study. JAMA Pediatr 2013;167:170–7.
17 Edelstein H, Schippke J, Shef JG, Hall M, Hall DE, et al. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev 2017;43:323–33.
18 Peakham A, Spalding K, Watkins J, et al. Caring for caregivers of high-needs children. Healthc Q 2011;14:73–5.
19 Lindahl B, Lindblad B-M. Family members’ experiences of everyday life when a child is dependent on a ventilator: a meta-synthesis study. J Fam Nurs 2011;17:241–69.
20 Yotani N, Ishiguro A, Sakai H, et al. Factor-associated caregiver burden in medically complex patients with special health-care needs. Pediatr Int 2014;56:742–7.
21 Carnevale FA, Alexander E, Davis M, et al. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. Pediatrics 2006;117:e48–60.
22 Barrera M, Hanceck K, Rokach A, et al. Does the use of the revised psychosocial assessment tool (PATrev) result in improved quality of life and reduced psychosocial risk in Canadian families with a child newly diagnosed with cancer? Psychooncology 2014;23:165–72.
23 Hears PJ, McCarthy MG, Muscara F, et al. Psychosocial risk in families of infants undergoing surgery for a serious congenital heart disease. Cardiol Young 2014;24:632–9.
Pai ALH, Tackett A, Ittenbach RF, et al. Psychosocial assessment tool 2.0. General: validity of a psychosocial risk screening tool in a pediatric kidney transplant sample. *Pediatr Transplant* 2012;16:92–8.

25 Tackett A, Ewertz M, Rostami H, et al. Caring for children and youth with medical complexity: can we do better? Available: https://www.blog.childrenshealthcarecanada.ca/blog/2018/5/29/caring-for-children-and-youth-with-medical-complexity-can-we-do-better

26 Wallis C, Paton JY, Beaton S, et al. Children on long-term ventilatory support: 10 years of progress. *Arch Dis Child* 2011;96:998–1002.

27 Pai ALH, Patiño-Fernández AM, McSherry M, et al. The psychosocial assessment tool (PAT2.0): psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol* 2008;33:50–62.

28 Thabrew H, McGovern I, Graven K, et al. Systematic review of screening instruments for psychosocial problems in children and adolescents with long-term physical conditions. *Glob Pediatr Health* 2017;4:2333794X1769031.

29 Karlson CW, Leist-Haynes S, Smith M, et al. Examination of risk and resiliency in a pediatric sickle cell disease population using the psychosocial assessment tool 2.0. *J Pediatr Psychol* 2012;37:1031–40.

30 Pai ALH, Tackett A, Hente EA, et al. Assessing psychosocial risk in pediatric inflammatory bowel disease: validation of the psychosocial assessment tool 2.0. General. *J Pediatr Gastroenterol Nutr* 2014;58:51–6.

31 Phan T-LT, Chen FF, Pinto AT, et al. Impact of psychosocial risk on outcomes among families seeking treatment for obesity. *J Pediatr* 2018;198:110–6.

32 Kazak AE. Pediatric psychosocial preventative health model (PPPHM): research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health* 2006;24:381–95.

33 Kazak AE, Barakat LP, Ditaranto S, et al. Screening for psychosocial risk at pediatric cancer diagnosis. *J Pediatr Hematol Oncol* 2011;33:289–94.

34 McCarthy MC, Clarke NE, Vance A, et al. Measuring psychosocial risk in families caring for a child with cancer: the psychosocial assessment tool (PAT2.0). *Pediatr Blood Cancer* 2009;53:78–83.

35 Alderfer MA, Moghiasi I, Barakat LP, et al. Family psychosocial risk, distress, and service utilization in pediatric cancer. *Cancer* 2009;115:4339–49.

36 Reader SK, Keeler CN, Chen FF, et al. Psychosocial screening in sickle cell disease: validation of the psychosocial screening tool. *J Pediatr Psychol* 2020;45:423–33.

37 Sharkey CM, Schepers SA, Drake S, et al. Psychosocial risk profiles among American and Dutch families affected by pediatric cancer. *J Pediatr Psychol* 2020;45:463–73.

38 Tsumura A, Okuyama T, Ito Y, et al. Reliability and validity of a Japanese version of the psychosocial assessment tool for families of children with cancer. *Jpn J Clin Oncol* 2020;50:296–302.

39 Filigno SS, Miller J, Moore S, et al. Assessing psychosocial risk in pediatric cystic fibrosis. *Pediatr Pulmonol* 2019;54:1391–7.

40 Kapa HM, Litteral JL, Pearson GD, et al. Assessment of psychosocial risk in families of children with craniofacial conditions using the psychosocial assessment Tool-Craniofacial version. *Cleft Palate Craniofac J* 2019;56:556–61.

41 Law EF, Powers SW, Blume H, et al. Screening family and psychosocial risk in pediatric migraine and tension-type headache: validation of the psychosocial assessment tool (PAT). *Headache* 2019;59:1516–29.

42 Hoqueque BG, Oztitoğlu A, Zimmerman K, et al. Distress and psychosocial risk in families with newly diagnosed pediatric brain tumors 2018;23:40.

43 Pai ALH, Swain AM, Chen FF, et al. Screening for family psychosocial risk in pediatric hematopoietic stem cell transplantation with the psychosocial assessment tool. *Biol Blood Marrow Transplant* 2019;25:1374–81.

44 Schulte F, Russell KB, Pelletier W, et al. Screening for psychosocial distress in pediatric cancer patients: an examination of feasibility in a single institution. *Pediatr Hematol Oncol* 2019;36:125–37.

45 Crérand CE, Kapa HM, Lind SA, et al. Identifying psychosocial risk factors among families of children with craniofacial conditions: validation of the psychosocial assessment Tool-Craniofacial version. *Cleft Palate Craniofac J* 2018;55:536–45.

46 Ernst MM, Gardner M, Mara CA, et al. Psychosocial screening in Disorders/Differences of sex development: psychometric evaluation of the psychosocial assessment tool. *Horm Res Paediatr* 2019:90:368–80.

47 Kazak AE, Hwang W-T, Chen FF, et al. Screening for family psychosocial risk in pediatric cancer: validation of the psychosocial assessment tool (PAT) version 3. *J Pediatr Psychol* 2018;43:737–48.

48 Cousino MK, Schumacher KR, Rea KE, et al. Psychosocial functioning in pediatric heart transplant recipients and their families. *Pediatr Transplant* 2018;22:e13110.

49 Woods K, Ostrowski-Delahanty S. Psychometric properties of the psychosocial assessment Tool–Chronic pain version in families of children with headache. *J Child Neurol* 2017;32:766–73.

50 Clapin H, Hop L, Ritchie E, et al. Home-based vs inpatient education for children newly diagnosed with type 1 diabetes. *Pediatr Diabetes* 2017;18:579–87.

51 Pierce L, Hocking MC, Schwartz LA, et al. Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment. *Psychooncology* 2017;26:1555–61.

52 McCarthy MC, DeGraves S, Wakefield CE, et al. The association of psychosocial screening and service provision in pediatric oncology: the psychosocial assessment tool (PAT2.0) into clinical practice. *Support Care Cancer* 2016;24:2945–52.

53 Sint Nicolaas SM, Schepers SA, Hoogerbrugge PM, et al. Screening for psychosocial risk in Dutch families of a child with cancer: reliability, validity, and usability of the psychosocial assessment tool. *J Pediatr Psychol* 2016;41:810–9.

54 Baldwin-Myers AS, Oppenheimer EA. Quality of life and quality of care data from a 7-year pilot project for home ventilator patients. *J Ambul Care Manage* 1996;19:46–59.

55 Sabbeth BF, Leventhal JM. Marital adjustment to chronic childhood illness: a critique of the literature. *Pediatrics* 1984:73:762.

56 Kuo DZ, Cohen E, Agrawal R, et al. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med* 2011;165:1020–6.

57 Patiño-Fernández AM, Pai ALH, Alderfer M, et al. Acute stress in parents of children newly diagnosed with cancer. *Pediatr Blood Cancer* 2008;50:289–92.