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Health-related quality of life and well-being in parents of infants and toddlers with cancer

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ABSTRACT

Background   The unique psychosocial needs of parents and caregivers of young children with cancer are poorly understood. The aims of the present study were to examine health-related quality of life (HRQOL), stress, and psychological distress in parents of young children (0–4 years) diagnosed with cancer; and the associations between parent psychosocial functioning and child treatment characteristics.

Methods   Parents ($n = 35$) with a child ($n = 19$ male, 54.3%) 0–48 months of age (median: 31.06 months) on active cancer therapy were recruited. Parents completed questionnaires related to demographics, parent HRQOL, parenting stress, posttraumatic stress symptoms, and parent psychological distress.

Results   Parents reported clinically elevated parenting stress (5.9%), posttraumatic stress symptoms (18.2%), and psychological distress (21.9%). Compared with population norms, parents reported lower HRQOL in the vitality ($t = 5.37$, $p < 0.001$), mental health ($t = 4.02$, $p < 0.001$), role limitation–emotional ($t = 3.52$, $p < 0.001$), and general health perceptions ($t = 2.25$, $p = 0.025$) domains. Social functioning ($\beta = 0.33$, $p = 0.041$) predicted general health perceptions; vitality ($\beta = 0.30$, $p = 0.134$) and parent mental health ($\beta = 0.24$, $p = 0.285$) did not [$F_{(3,29)} = 12.64$, $p < 0.001$, $R^2 = 0.57$].

Conclusions   A subset of parents of young children on active cancer treatment experience clinically elevated psychosocial symptoms. Having poor social connections put parents at risk of perceiving their health more poorly in general. Supports that focus on preventing the emergence of clinically significant distress should focus on parents of young children with cancer who are most at risk of poor outcomes.

Key Words   Pediatric cancer, infants, parents, stress, health-related quality of life, psychological distress

INTRODUCTION

Infancy and toddlerhood are a period of unique and intensive parenting stress and responsibility. Children less than 4 years of age are twice as likely to be diagnosed with cancer than older children, and yet there is a dearth of literature examining the unique psychosocial factors influencing the parents and caregivers of those young children[1,2]. The paucity of research is particularly striking, because infancy and early childhood are a rapid period of growth and brain development that lay the foundation for physical and mental health throughout the lifespan[3]. It is also the developmental period when the parent–child relationship is being established[4]—a bond that can be disrupted by hospitalizations and extended treatments for cancer. Pediatric cancer diagnosis and treatment can put considerable strain on parental well-being, and understanding better the specific challenges and their impacts is necessary to adequately meet the psychosocial needs of parents and caregivers of young children.

It has been well established that parent well-being is central to the quality of life and psychosocial adjustment of children with cancer[5]. The social-ecological model of childhood cancer purports that children diagnosed with cancer are inextricably linked to the setting and context around them, including their parents or caregivers[6,7].

Parents and family members thus play a critical role in influencing the psychosocial adaptation of children with cancer[7–9]. Broadly, research about parents of children diagnosed with cancer has demonstrated several psychosocial challenges related to the experience, including reduced quality of life[10–12], elevated stress[11,13–15], and psychological distress[16]. Furthermore, parent stress and psychological distress have been associated with poorer outcomes for children diagnosed with cancer[17].

Although the association between parent and child well-being in the pediatric oncology context has been well established, the relevant research includes children of diverse ages, ranging from birth to 20 years. Although that work provides information about parent psychosocial adjustment more broadly, it does not allow for the identification of the unique needs of parents based on their child's developmental stage. Furthermore, pediatric cancer diagnoses have varying prevalence rates based on child age. For example, young children are more likely to be diagnosed with leukemias and solid tumours (such as muscle and central nervous system tumours), and adolescents are more likely to be diagnosed with lymphomas and osteosarcomas, resulting in potentially different outcomes for the child and the parent[18]. Understanding the unique psychosocial needs of parents of young children with cancer—and the predictors of these needs—will facilitate the targeting of tailored interventions to reduce distress in that population.

A small body of research investigating the well-being of parents of young children with cancer[16,19] has identified that more psychological distress is experienced by parents of children with cancer between 2 and 5 years of age than by community controls[16]. Parent distress has been shown to be higher when there are other children in the household and to decline over the 1st year of the child's diagnosis[19]. The present study builds on that work by examining whether additional treatment characteristics (days hospitalized, treatment intensity, child sex, and household income) relate to parent psychosocial functioning. Furthermore, missing from the current literature is an understanding of health-related quality of life (HRQOL) for parents of young children with cancer and how demographic and treatment characteristics influence parent HRQOL. In the present study, we address that research gap by investigating associations between parent psychosocial functioning (HRQOL, parenting stress, posttraumatic stress, psychological distress), child treatment characteristics (time since diagnosis, days hospitalized, treatment intensity), and sociodemographic factors (child age, child sex, parent age, parent education, household income) in parents of young patients with cancer.

The objectives of the present study were to

- assess HRQOL, parenting stress, posttraumatic stress, and psychological distress in a population of caregivers of young children (<4 years of age) diagnosed with cancer; and
- identify whether treatment characteristics (time since diagnosis, days hospitalized, treatment intensity) and sociodemographic factors (child age, child sex, parent age, parent education, household income) are associated with parenting stress, posttraumatic stress, psychological distress, and HRQOL.

Based on previous research[20], we hypothesized that, compared with normative groups, parents of young children diagnosed with cancer would demonstrate elevated levels of parenting stress, posttraumatic stress, and psychological distress (hypothesis 1A) and low levels of HRQOL relative to population means (hypothesis 1B). We also hypothesized that younger parents; parents with a lower household income; and parents whose children were younger, who had been diagnosed more recently, who had been hospitalized for more days, and who had received more intense treatment courses would have worse outcomes in terms of parenting stress, posttraumatic stress, psychological distress, and HRQOL (hypothesis 2)[12,14,21].

METHODS

Participants
Participants included parent–child dyads recruited from the Alberta Children's Hospital Hematology, Oncology, and Transplant Program. Inclusion criteria were

- the child was between 0 and 4 years of age and receiving treatment for cancer;
- the child must have received the diagnosis more than 1 month before participation to avoid assessment of acute adjustment;
- the child had no previous evidence of intellectual disability or genetic disorder causing intellectual disability; and
- the primary caregiver could speak, read, and write English.

Procedures
All procedures were approved by the Health Research Ethics Board of Alberta–Cancer Committee. Patients were identified from oncology clinic lists, and parents of eligible children were approached by telephone. If the parent indicated interest in participating, questions were asked to further determine eligibility. Families that met the inclusion criteria were sent a questionnaire package and an addressed and stamped return envelope by postal mail. The questionnaires took 60–75 minutes to complete and were expected to be returned by postal mail using the supplied envelope. If the questionnaires were not returned, parents received a reminder telephone call once each month for 3 months. If the questionnaires were not returned after 3 telephone reminders, parents were asked if they would prefer to complete the questionnaires electronically. To complete the questionnaires online, parents were sent a unique private and confidential link to the questionnaires.

Measures

Demographics
A demographic questionnaire was used to assess the age, sex, and ethnicity of the child, and the age, education status, and income of the parents.

Parenting Stress
The Parenting Stress Index–Short Form (PSI-SF: Abidin RR, Lutz, FL, U.S.A.) is a 36-item questionnaire designed for

use with parents of children aged 1 month to 12 years. It has 3 subscales: parental distress, with items measuring distress based on personal factors such as perception of parenting incompetence, depression, and restrictions on life roles as a result of parenting demands; parent–child dysfunctional interaction, with questions measuring the parent's expectations of their child and dissatisfaction about interactions with their child; and difficult child, with items measuring parent perceptions of their child's self-regulation behaviors[22]. The items of the PSI-SF are rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The PSI-SF also contains a defensive responding score that ranges from 7 to 35, which indicates whether a parent is minimizing concerns about their child or has a bias toward underreporting concerns. A score of 10 or less indicates that a parent has responded in a defensive manner. The PSI-SF has good test–retest reliability and a high degree of internal consistency[22]. Means for parenting stress reflect the percentile for participants (from 0 to 100). Participants with scores above the 90th percentile were considered to have clinical levels of parenting stress.

Posttraumatic Stress

The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5: United States, Department of Veterans Affairs, National Center for PTSD, Washington, DC, U.S.A.) is a 20-item self-report questionnaire that measures an individual's posttraumatic stress symptoms, per the *Diagnostic and Statistical Manual of Mental Disorders,* 5th edition. Participants were asked to rate how much they were bothered by certain symptoms in the past month on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). One sample question from the PCL-5 is "In the past month, how much were you bothered by repeated, disturbing, and unwanted memories of the stressful experience?" The PCL-5 has been shown to have strong test–retest reliability, internal consistency, and discriminant and convergent validity[23]. The means for posttraumatic stress reflect the raw scores on the PCL-5, which range from 0 to 80. Parents with raw scores of 33 or higher are identified as having a potential diagnosis of posttraumatic stress disorder.

Parent Psychological Distress

The Brief Symptom Inventory (Derogatis LR, Bloomington, MN, U.S.A.) is a 53-item self-report scale that is summarized in a Global Severity Index. It has 10 subscales, including somatization, obsessive–compulsive tendencies, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychotic tendencies. Participants are presented with items consisting of problems people sometimes have, and they are asked to rate how much they had been distressed by that problem in the preceding week by rating it on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). The Brief Symptom Inventory has demonstrated strong validity and reliability[24]. The means for parent psychological distress reflect the participant's T scores. Parents who reported mental health symptoms with a T score of 63 or higher on the Global Severity Index were deemed to have clinical levels of psychological distress.

Parent HRQOL

The 36-item Short Form Survey (SF-36: RAND Corporation, Santa Monica, CA, U.S.A.) is a self-report measure that assesses adult HRQOL in 8 domains, including physical functioning, role limitations because of physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations because of emotional problems, and mental health[25]. A sample question from the SF-36 says "Compared to one year ago, how would you rate your health in general now?" Each domain has scores ranging from 0 to 100, with higher scores indicating better HRQOL. The SF-36 has excellent internal consistency and discriminant validity[26]. The means for HRQOL for each domain were compared with Canadian normative data to determine whether the participants in the current study differed from the general population[27].

Child Medical Characteristics

The Intensity of Treatment Rating scale (version 3) is a form that determines the severity of a patient's disease and treatment based on stage and risk level, relapse, and treatment modality, including surgery, radiation, chemotherapy, and blood and marrow transplantation[28]. Using the criteria on the form, a patient's treatment intensity is categorized between 1 (low treatment intensity) and 4 (high treatment intensity). Treatment intensity is a proxy for disease severity. The Intensity of Treatment Rating scale is a reliable and valid measure and was completed by the oncologist on the research team.

Medical charts were also reviewed to determine the number of days hospitalized, time since diagnosis (in days); and whether the child had relapsed (1, yes; 0, no) or had undergone surgery (1, yes; 0, no), radiation (1, yes; 0, no), chemotherapy (1, yes; 0, no), or transplantation (1, yes; 0, no).

Statistical Analyses

Descriptive analyses were performed to identify participant and variable characteristics, including means, standard deviations, and ranges. Frequencies were calculated to determine the prevalence of parents who met clinical levels of parenting stress, posttraumatic stress, and psychological distress (hypothesis 1A). Independent-samples *t*-tests were conducted to determine any differences in mean HRQOL between the study participants and normative data for Canadians (hypothesis 1B)[27]. The mean age of the study participants was used to match them with similar-aged individuals from the Canadian normative data. To test hypothesis 2, independent-samples *t*-tests (for binary data) and Pearson correlational coefficients (for continuous variables) were calculated to examine relationships between sociodemographic factors, treatment characteristics, and parent psychosocial functioning. Variables were selected based on high associations and significant ($p < 0.05$) correlations, were checked for multicollinearity, and were entered into 4 separate multiple regression analyses to demonstrate their ability to predict parenting stress, posttraumatic stress, psychological distress, and HRQOL. To ensure adequate power, given the small sample size, only 3 independent variables were entered into each regression model. Analyses were conducted using the IBM SPSS Statistics software application (version 24: IBM, Armonk, NY, U.S.A.).

RESULTS

Descriptive Findings

As shown in Figure 1, 105 primary caregivers were assessed for eligibility, with 55 being excluded (45 did not meet the inclusion criteria, and 10 declined participation). Primary caregivers were excluded because their child had a neurologic, immunologic, or nonmalignant blood disorder (37.8%); their child was more than 4 years of age (11.1%); their child had an intellectual disability (11.1%); their child did not have a history of cancer, but instead was being screened for cancer (6.7%); their child was off treatment (6.7%); their child was receiving treatment primarily at another site (6.7%); their child had passed away (2.2%); or they could not speak or read English (2.2%). In the remaining cases, the reason was unknown (15.6%). Primary caregivers declined participation because they were not interested in participating (60%), had already participated in a similar study (20%), were too busy (10%), or thought it would be too difficult to participate because English was not their first language (10%). Completed questionnaires were received from 35 participants (70% response rate). Of the complete questionnaires, 6 (17.1%) had been submitted electronically.

Of the 35 parents who participated, 33 were mothers, and 2 were fathers. The average parent age was 32.00 years (range: 21–41 years). Most parents had postsecondary education (71.5%) and a household income of $70,000 or more. The average child age was 31.06 months (range: 3–59 months), with 54.3% being male and most being white (68.6%). The most common cancer diagnosis was acute leukemia (22.9%). Table I presents complete demographic information for the participants.

Aim 1: Frequencies

Table II shows the means for all study variables. Of the responding participants (*n* = 34), 2 (5.9%) reported experiencing total parenting stress in the clinical range, and 6 (17.6%) had a result of 10 or less on the defensive responding score within the PSI-SF, indicating that they might have responded in a defensive manner.

Of the responding participants (*n* = 33), 6 (18.2%) reported experiencing posttraumatic stress in the clinical
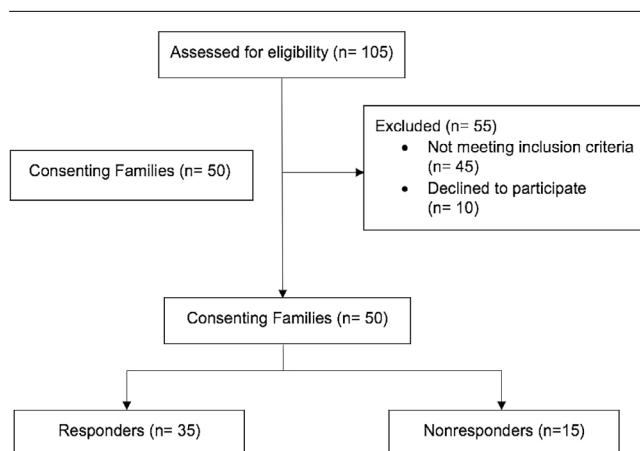

FIGURE 1 Study recruitment flowchart.

TABLE I Participant characteristics

Characteristic	Value
Child age (months)	
Mean	31.06±15.04
Range	3–59
Days hospitalized	
Mean	32.2±34.54
Range	1–139
Time since diagnosis (days)	
Mean	356.46±358.61
Range	37–1415
Parent age (years)	
Mean	32.00±5.30
Range	21–41
Child sex [*n* (%)]	
Boys	19 (54.3)
Girls	16 (45.7)
Parent sex [*n* (%)]	
Men	2 (5.7)
Women	33 (94.3)
Child ethnicity [*n* (%)]	
Asian	2 (5.7)
White	24 (68.6)
Hispanic	1 (2.9)
Multiple	2 (5.7)
Other	4 (11.4)
Missing	2 (5.7)
Parent education [*n* (%)]	
High school	10 (28.6)
College	8 (22.9)
University	12 (34.3)
Graduate or professional school	5 (14.3)
Household income [*n* (%)]	
>$100,000	12 (34.3)
$70,000–$100,000	12 (34.3)
$50,000–$70,000	4 (11.4)
$20,000–$50,000	2 (5.7)
<$20,000	1 (2.9)
Missing	4 (11.4)
Child cancer diagnosis [*n* (%)]	
Acute lymphoblastic leukemia	8 (22.9)
Neuroblastoma	4 (11.4)
Hepatoblastoma	4 (11.4)
Wilms tumour	3 (8.6)
Rhabdomyosarcoma	3 (8.6)
Langerhans cell histiocytosis	3 (8.6)
Acute myeloid leukemia	2 (5.7)
Medulloblastoma	2 (5.7)
Pilocytic astrocytoma	2 (5.7)
Burkitt lymphoma	1 (2.9)
Atypical teratoid or rhabdoid tumour	1 (2.9)
Mesoblastic nephroma	1 (2.9)
Ganglioglioma	1 (2.9)

TABLE I Continued

Characteristic	Value
Relapse [*n* (%)]	6 (17.1)
Treatment [*n* (%)]	
Surgery	18 (51.4)
Radiation	5 (14.3)
Chemotherapy	27 (77.1)
Transplantation	8 (22.9)
Treatment intensity [*n* (%)]	
1 (low)	8 (22.9)
2	6 (17.1)
3	11 (31.4)
4 (high)	10 (28.6)

range. However, almost all ($n = 32$, 97%) reported experiencing at least 1 symptom of posttraumatic stress disorder (for example, repeated, disturbing, and unwanted memories), and 7 (21.2%) reported experiencing psychological distress in the clinical range. The prevalences of clinical elevations were also examined for the responding participants ($n = 32$) in notable Brief Symptom Inventory subscales: 43.8% ($n = 14$) reported obsessive–compulsive tendencies, 21.9% ($n = 7$) reported depressive symptoms, 34.4% ($n = 11$) reported anxiety symptoms, 21.9% ($n = 7$) reported hostility symptoms, and 25% ($n = 8$) reported phobic anxiety symptoms.

Compared with population norms, HRQOL was lower for study parents in 4 of the 8 domains, including vitality ($t = 5.37$, $p < 0.001$), mental health ($t = 4.02$, $p < 0.001$), role limitation–emotional ($t = 3.52$, $p < 0.001$), and general health perceptions ($t = 2.25$, $p = 0.025$). No differences were observed between population norms and HRQOL for the study parents in the domains of social functioning ($t = 1.16$, $p = 0.246$), physical functioning ($t = 1.20$, $p = 0.232$), role limitation–physical ($t = 1.86$, $p = 0.063$), and bodily pain ($t = 0.99$, $p = 0.323$).

Aim 2: Associations

Independent-Samples t-Tests: Some significant differences were found between parent psychosocial functioning and binary data such as child sex and treatment-related characteristics (surgery and chemotherapy). Parents who had a female child with cancer reported higher levels of physical functioning than did parents who had a male child with cancer ($t = -2.09$, $p = 0.045$). Parents whose child had surgery experienced lower levels of parenting stress than did parents whose child did not have surgery ($t = -2.08$, $p = 0.045$). Parents with a child who had received chemotherapy reported less role limitation because of physical problems than did parents with a child who had not received chemotherapy ($t = 2.44$, $p = 0.021$). Table III lists all independent-samples *t*-test findings.

Correlation Analysis: Demographic factors and treatment-related characteristics were found to be significantly associated with parent psychosocial functioning. Child age and parent vitality were associated ($r = 0.40$, $p = 0.022$) such that parents with younger children reported more fatigue. Parent age was significantly associated with social functioning ($r = -0.37$, $p = 0.037$), bodily pain ($r = -037$,

TABLE II Parent psychological distress, parenting stress, posttraumatic stress, and health-related quality of life

Variable	Response		
	[*n* (%)]	Mean	Range
Parent psychological distress			
Global Severity Index	32 (91.4)	56.66±11.01	33–80
Parenting stress			
Parenting stress	34 (97.1)	43.12±28.067	1–98
Parenting stress (excluding defensive responders)	28 (80.0)	50.43±25.79	6–98
Defensive responding score	34 (97.1)	15.64±5.79	7–31
Posttraumatic stress			
PCL total	33 (94.3)	21.30±17.48	0–80
Health-related quality of life			
Physical functioning	34 (97.1)	87.35±24.22	30–100
Role functioning–physical	33 (94.3)	75.00±36.44	0–100
Bodily pain	33 (94.3)	81.29±24.09	10–100
General health perceptions	34 (97.1)	69.52±23.73	15–100
Vitality	33 (94.3)	40.61±25.46	0–100
Social functioning	33 (94.3)	81.29±24.09	10–100
Role functioning–emotional	33 (94.3)	57.32±40.65	0–100
Mental health	33 (94.3)	59.15±23.51	12–100

PCL = Posttraumatic Stress Disorder Checklist for DSM-5 (United States, Department of Veterans Affairs, National Center for PTSD, Washington, DC, U.S.A.).

$p = 0.037$), and role limitation–physical ($r = -040$, $p = 0.022$) such that older parents had poorer social functioning, had more bodily pain, and were more limited in their role because of physical problems. Days since diagnosis was correlated with psychological distress ($r = -048$, $p = 0.006$), vitality ($r = 0.60$, $p < 0.001$), and mental health ($r = 0.41$, $p = 0.017$), indicating that, over time, parents had less psychological distress, more energy, and better mental health. Parenting stress, posttraumatic stress, psychological distress, and HRQOL were not associated with annual household income, days hospitalized, or treatment intensity, but parent psychosocial factors were significantly associated with one another. Table IV lists all correlation findings.

Multiple Regression Analysis: Four linear regression models were constructed using parenting stress, posttraumatic stress, psychological distress, and HRQOL as criterion variables. Table V presents the results of the regression analyses. The first model, which used parenting stress as the criterion variable, was significant. Posttraumatic stress ($\beta = 0.30$, $p = 0.206$), parent psychological distress ($\beta = 0.20$, $p = 0.426$), and parent mental health ($\beta = -0.21$, $p = 0.409$) accounted for 41% of the variance in parenting stress ($F_{(3,28)} = 6.41$, $p = 0.002$, $R^2 = 0.41$), but no predictor

TABLE III Summary of independent-samples *t*-tests of sociodemographic, treatment-related, and parent psychosocial functioning variables

Measures	Child sex		Relapse		Surgery		Radiation		Chemotherapy		Transplantation	
	Mean (boys, girls)	t	Mean (yes, no)	t	Mean (yes, no)	t	Mean (yes, no)	t	Mean (yes, no)	t	Mean (yes, no)	t
1 Parenting stress	48.37, 36.47	1.21	40.50, 43.19	−0.20	33.06, 53.13	−2.08[a]	50.40, 41.26	0.63	43.59, 39.17	0.33	31.50, 46.40	−1.28
2 Posttraumatic stress	24.21, 17.36	1.12	26.80, 20.46	0.74	21.44, 22.38	−0.15	32.00, 19.93	1.30	20.88, 26.33	−0.69	16.71, 23.36	−0.89
3 Psychological distress	57.74, 55.08	0.67	56.80, 56.20	0.11	52.67, 60.44	−2.03	57.50, 56.12	0.23	56.44, 57.67	−0.24	55.71, 56.96	−0.26
4 Physical functioning	80.00, 96.67	−2.09[a]	91.67, 88.08	0.35	85.00, 89.06	−0.47	90.00, 88.52	0.13	89.42, 77.86	1.11	86.88, 87.00	−0.01
5 Role functioning–physical	73.68, 76.79	−0.24	90.00, 70.19	1.10	70.31, 78.13	−0.60	75.00, 73.15	0.09	82.00, 46.43	2.44[a]	78.57, 73.00	0.35
6 Bodily pain	78.16, 85.54	−0.87	80.50, 81.25	−0.06	79.06, 82.34	−0.38	78.13, 81.57	−0.26	82.20, 75.36	0.65	83.21, 80.00	0.31
7 General health perceptions	69.41, 69.67	−0.03	60.83, 71.68	−0.98	71.99, 66.56	0.64	53.00, 72.73	−1.71	68.85, 71.25	−0.23	71.25, 68.75	0.25
8 Vitality	43.16, 37.14	0.67	50.00, 39.42	0.84	48.13, 32.50	1.77	32.50, 42.41	−0.71	38.40, 47.14	−0.79	43.57, 39.40	0.37
9 Social function	78.16, 85.54	−0.87	80.50, 81.25	−0.06	79.06, 82.34	−0.38	78.13, 81.57	−0.26	82.20, 75.36	0.65	83.21, 80.00	0.31
10 Role functioning–emotional	56.58, 58.33	−0.12	50.00, 57.37	−0.36	59.38, 52.60	0.47	43.75, 58.02	−0.64	61.67, 35.71	1.53	57.14, 55.67	0.08
11 Mental health	58.53, 60.00	−0.18	60.00, 59.69	0.03	63.25, 55.00	0.98	43.00, 62.22	−1.53	58.56, 61.14	−0.25	62.86, 58.08	0.46
12 Parent age	31.00, 33.13	−1.17	29.33, 32.62	−1.35	32.18, 31.69	0.26	34.60, 31.52	1.17	31.56, 33.67	−0.87	33.38, 31.48	0.87
13 Parent education	2.05, 2.69	−1.83	1.67, 2.56	−1.94	2.44, 2.25	0.52	2.00, 2.46	−0.90	2.37, 2.29	0.18	2.38, 2.35	0.07
14 Household income	3.88, 4.21	−0.87	2.60, 4.30	−3.98[b]	4.25, 3.79	1.20	3.67, 4.04	−0.56	3.96, 4.33	−0.77	4.00, 4.04	−0.09
15 Child age (months)	34.21, 27.31	1.37	34.83, 30.30	0.65	33.44, 28.06	1.03	36.20, 30.21	0.80	31.89, 27.14	0.73	34.00, 29.96	0.65
16 Days hospitalized	35.63, 28.13	0.64	54.17, 25.81	1.85	20.44, 44.00	−2.06[a]	57.20, 26.29	1.88	38.33, 5.29	2.39[a]	63.00, 21.85	3.34[c]
17 Days since diagnosis	390.2, 316.4	0.60	476.8, 304.9	1.09	434.1, 227.9	1.80	376.8, 328.9	0.28	360.9, 245.1	0.79	399.5, 317.9	0.58
18 Treatment intensity	2.95, 2.31	1.69	3.83, 2.33	3.33[c]	2.33, 3.00	−1.74	3.20, 2.50	1.27	3.04, 1.14	5.18[b]	4.00, 2.23	4.99[b]

[a] *p* < 0.05.
[b] *p* < 0.001.
[c] *p* < 0.01.

TABLE IV Correlations between sociodemographic, treatment-related, and parent psychosocial functioning variables

Measures	1 Parenting stress	2 Posttraumatic stress	3 Psychological distress	4 Physical functioning	5 Role functioning–physical	6 Bodily pain	7 General health perceptions	8 Vitality	9 Social function	10 Role functioning–emotional	11 Mental health
1 Parenting stress	—										
2 Posttraumatic stress	0.59[a]	—									
3 Psychological distress	0.57[b]	0.72[a]	—								
4 Physical functioning	–0.42[c]	–0.39[c]	–0.36[c]	—							
5 Role functioning–physical	–0.22	–0.36[c]	–0.47[b]	0.42[c]	—						
6 Bodily pain	–0.34	–0.43[c]	–0.48[b]	0.60[a]	0.59[a]	—					
7 General health perceptions	–0.48[b]	–0.61[a]	–0.61[a]	0.54[b]	0.44[c]	0.63[a]	—				
8 Vitality	–0.56[b]	–0.50[b]	–0.68[b]	0.40[c]	0.26	0.49[b]	0.65[a]	—			
9 Social function	–0.34	–0.43[c]	–0.48[b]	0.60[a]	0.59[a]	1.00[a]	0.63[a]	0.49[b]	—		
10 Role functioning–emotional	–0.33	–0.55[b]	–0.64[a]	0.37[c]	0.71[a]	0.63[a]	0.52[b]	0.48[b]	0.63[a]	—	
11 Mental health	–0.58[b]	–0.73[a]	–0.77[a]	0.35[c]	0.34	0.62[a]	0.68[a]	0.78[a]	0.62[a]	0.65[a]	—
12 Parent age	0.20	–0.19	–0.09	–0.17	–0.40[c]	–0.37[c]	–0.15	0.04	–0.37[c]	–0.20	–0.04
13 Parent education	–0.06	0.27	–0.17	0.13	0.04	0.19	0.04	0.05	0.19	0.13	0.06
14 Household income	0.11	–0.09	–0.26	–0.10	–0.11	–0.004	0.22	0.05	–0.004	–0.06	0.03
15 Child age	0.04	–0.22	–0.34	0.10	–0.17	–0.01	0.17	0.40[c]	–0.01	–0.04	0.23
16 Days hospitalized	–0.15	–0.19	–0.04	0.19	0.10	0.06	0.001	–0.01	0.06	0.07	0.11
17 Days since diagnosis	0.02	–0.30	–0.48[b]	0.18	0.19	0.19	0.30	0.60[a]	0.19	0.34	0.41[c]
18 Treatment intensity	–0.10	–0.24	–0.14	0.08	0.29	0.10	0.04	0.06	0.10	0.13	0.16

[a] $p < 0.001$
[b] $p < 0.01$
[c] $p < 0.05$

TABLE V Regression analyses for parenting stress, posttraumatic stress, psychological distress, and general health as criterion variables

Model	B	SE	ß	R²	F	df	p Value
Criterion variable: parenting stress				0.41	6.41	3,28	0.002
Posttraumatic stress	0.49	0.38	0.30				0.206
Psychological distress	0.53	0.65	0.20				0.426
Mental health	−0.26	0.31	−0.21				0.409
Criterion variable: posttraumatic stress				0.61	14.29	3,28	0.000
Psychological distress	0.58	0.31	0.36				0.069
General health perceptions	−0.11	0.12	−0.16				0.351
Mental health	−0.26	0.15	−0.35				0.105
Criterion variable: psychological distress				0.68	19.55	3,28	0.000
Posttraumatic stress	0.23	0.10	0.38				0.025
Vitality	−0.12	0.07	−0.27				0.131
Mental health	−0.13	0.10	−0.29				0.206
Criterion variable: general health perceptions				0.57	12.64	3,29	0.000
Vitality	0.28	0.18	0.30				0.134
Mental health	0.24	0.22	0.24				0.285
Social functioning	0.329	0.15	0.33				0.041

B = unstandardized beta; SE = standard error.

was significant. Again in the second model, no predictor was significant. Parent psychological distress (β = 0.36, *p* = 0.069), general health perceptions (β = −0.16, *p* = 0.351), and parent mental health (β = −0.35, *p* = 0.105) accounted for 61% of the variance in posttraumatic stress ($F_{(3,28)}$ = 14.29, *p* < 0.001, R^2 = 0.61). The third model, which contained posttraumatic stress (β = 0.38, *p* = 0.025), vitality (β = −0.27, *p* = 0.131), and parent mental health (β = −0.29, *p* = 0.206), was significant and accounted for 68% of the variance in psychological distress ($F_{(3,28)}$ = 19.56, *p* < 0.001, R^2 = 0.68). Posttraumatic stress emerged as a significant predictor. The last model, which used general health perceptions as the criterion variable was also significant. Vitality (β = 0.30, *p* = 0.134), parent mental health (β = 0.24, *p* = 0.285), and social functioning (β = 0.33, *p* = 0.041) accounted for 57% of the variance in general health perceptions ($F_{(3,29)}$ = 12.64, *p* < 0.001). Social functioning emerged as a significant predictor.

DISCUSSION

Results of the present study showed that, although most parents of young children (0–4 years) with cancer reported low parenting stress and low psychological distress, a select group reported experiencing clinically significant parenting stress, posttraumatic stress, and psychological distress. Compared with normative data, study parents also reported less vitality, poorer mental and general health, and more limitations in their role because of emotional problems. Associations between demographic factors, treatment-related characteristics, and parent psychosocial functioning were also found.

The prevalences of study parents experiencing clinical levels of parenting stress, posttraumatic stress, and psychological distress were 5.9%, 18.2%, and 21.9% respectively. Those prevalence rates are generally lower than rates found using the same measures in other studies examining

stress and psychological distress in parents of children with cancer[19,29,30]. For example, Vernon *et al.*[19] found that approximately 37% of parents of children less than 2 years of age with cancer reported experiencing posttraumatic stress symptoms in the clinical range, and the study by Fuemmeler *et al.*[29] found that 49% of parents of children with cancer (mean age: 13.8 years) reported psychological distress in the clinical range. Although, in comparison with normative data, the parents in the present study had less vitality, poorer mental and general health, and limitation in their role because of emotional problems, they did not differ from the norm in terms of physical and social functioning, bodily pain, or limitation in their role because of physical problems. Those findings differ from earlier work[12] in which parents of a child with cancer experienced worse HRQOL compared with normative data in 7 of the 8 domains.

There are several potential reasons for the low prevalence of clinically elevated psychosocial symptoms in the present study. The socioeconomic status of the parents in our sample was, on average, higher than that seen in previous studies, indicating that parents might have had more access to instrumental supports and less financial concern[29]. Furthermore, the present study was conducted in a publicly funded health care system, posing less of a financial burden to the family than might occur in other jurisdictions. Another possibility is that parents withheld information about their parenting stress. Previous research has examined the relationship between parent adaptive style and posttraumatic stress in pediatric oncology settings[31]. Those authors found that parents who had a repressive style (responding so as to present themselves favourably) reported lower levels of posttraumatic stress than did those who did not have a repressive style. A higher percentage of those parents might therefore be experiencing clinical levels of psychosocial distress, but not be forthcoming about those difficulties.

We observed some of the expected associations between sociodemographic factors, treatment-related characteristics, and parent psychosocial functioning. Parents who were older reported poorer social functioning, more bodily pain, and more limitation in their role because of physical problems. That finding might be more reflective of mothers, given that only 2 fathers participated in the study. Parents with younger children also experienced lower levels of vitality, reinforcing the importance of understanding the unique psychosocial difficulties of parents of young children with cancer. Consistent with previous studies, parents reported less psychological distress, fewer mental health problems, and higher levels of vitality as the time since their child's diagnosis increased[32], suggesting that parents might adapt to the diagnosis and treatment over time. Associations between parenting stress, posttraumatic stress, psychological distress, and HRQOL were not associated with annual household income, days hospitalized, and treatment intensity.

We also observed two unexpected findings from the independent-samples *t*-tests. First, parents whose child had surgery reported lower levels of parenting stress than did parents whose child did not have surgery. Similarly, parents whose child received chemotherapy reported less role limitation because of physical problems than did parents whose child did not receive chemotherapy. Although those findings might suggest that a child's receipt of surgery or chemotherapy is a protective factor for the parent's psychosocial functioning, we interpreted the findings differently. One possible explanation is that the surgery and chemotherapy might have been successful and thus a relief for the parents. Another possible explanation is that the child's treatments were completed, and the other children had yet to receive surgery or chemotherapy. The parents of the latter group might have felt more stressed and limited in their role because of the child's looming treatments. We did not ask parents about treatment success or upcoming treatments and procedures, and so future research could investigate whether those factors affect the parent's psychosocial functioning.

Results of the regression analyses showed that certain parent psychosocial factors predicted parent psychological distress and general health perceptions, but not parenting stress and posttraumatic stress. The first model demonstrated that posttraumatic stress, parent psychological distress, and parent mental health did not predict parenting stress. Similarly, the second model found that parent psychological distress, general health perceptions, and parent mental health did not predict posttraumatic stress. The third model indicated that parents who had high levels of posttraumatic stress also had high levels of psychological distress. The final model revealed that parents who had better social functioning also tended to have a better perception about their health in general. That finding highlights a parent's need for social support more broadly, with tailored supports offered to families who have concerns about their health in general. Support to parents, in the form of parent support groups, might help to reduce parent distress and mitigate poor outcomes for the child[33,34].

Findings from the present study should be interpreted in the context of some limitations. First, the study captured a small number of participants of relatively high socioeconomic status, which limits the generalizability of the findings to populations with higher sociodemographic risk. Second, given the correlational nature of the current study, causal claims cannot be made about the relationships between the variables. Finally, only 1 caregiver completed the questionnaires, most of whom were mothers, resulting in an incomplete picture of the psychosocial experience of both parents of infants and toddlers with cancer.

The results of the study provide researchers and practitioners with crucial information about the experiences of parents of infants and toddlers diagnosed with cancer. Results indicating elevated levels of parent psychological distress, parenting stress, posttraumatic stress, and reduced levels of HRQOL, as well as associations between demographic factors, treatment-related characteristics, and parent psychosocial functioning point to the importance of future research to explore intervention programs that could potentially target this unique population of parents. Support and interventions might be warranted specifically for parents who are older, who have high levels of posttraumatic stress, who are socially isolated, and who have a child recently diagnosed with cancer. To identify parents who are in need of further psychosocial care, assessment of parent well-being and HRQOL should be integrated into routine medical appointments.

Other directions for future research include obtaining reports from more than 1 caregiver, obtaining matched healthy control participants to evaluate differences in parent psychological distress, parenting stress, posttraumatic stress, and HRQOL between parents of children with cancer and parents of healthy children. Future research should also include social support as a potential moderator for associations between sociodemographic factors, treatment-related characteristics, and parent psychosocial functioning. Lastly, future directions should include understanding the unique treatment and intervention needs of this parent population.

CONCLUSIONS

Primary caregivers of infants and toddlers with cancer who are receiving active treatment are at risk of poor HRQOL, psychological distress, parenting stress, and posttraumatic stress. We found that poor parent outcomes were predicted by parent psychosocial functioning. Taken together, the findings suggest that prevention and intervention efforts to support parents who have a young child with cancer are needed and might ultimately improve the psychosocial functioning of this unique population.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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