

The Association of Perceived Social Support with Anxiety over Time in Parents of Children with Serious Illnesses

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Abstract

Background: Parenting a child with a serious life-threatening illness (SLTI) may impact parents' mental health. The protective association of social support with anxiety over time following an acute medical event has not been empirically tested in a sample of parents of children with oncologic and nononcologic serious illnesses.

Objective: To test the potential association of perceived social support with anxiety in parents of children with SLTIs over time.

Design: Prospective cohort study.

Setting/Subjects: Two hundred parents of 158 children in the Decision Making in Serious Pediatric Illness study, conducted at the Children's Hospital of Philadelphia.

Measurements: Parental anxiety and perceived social support were assessed using the Hospital Anxiety and Depression Scale (HADS) and the Social Provisions Scale (SPS). We performed bivariate linear regressions to test cross-sectional and longitudinal associations between the SPS and anxiety scores at baseline, 12 months, and 24 months.

Results: The average SPS total and subscale scores decreased significantly from baseline to 12 months, and increased from 12 to 24 months. The average HADS-Anxiety scores decreased significantly from baseline to 12 months, and remained stable at 24 months. Cross-sectionally, total SPS scores were negatively associated with anxiety scores at each time point. Longitudinally, SPS scores were associated with anxiety scores, although this association weakened in adjusted modeling.

Conclusions: Over a two-year period, higher levels of perceived social support were associated with lower levels of anxiety in parents of seriously ill children. Clinicians and researchers should work to optimize social support for families to improve parental mental health outcomes.

Keywords: anxiety; children with serious illness; parents; social support

Introduction

PARENTING A CHILD with a serious life-threatening illness (SLTI) is remarkably demanding. In addition to serious physical, financial, and psychosocial implications,¹⁻⁴ parents' mental health is particularly adversely affected^{1,2,4-14}; psychological distress is reported to be present in as many as 70% of these parents,¹² and clinical anxiety and depression in as many as 25-28%.^{13,15}

Perceived social support, defined as the "subjective judgment that family and friends would provide quality assistance during times of trouble,"¹⁶ may improve the mental well-being

of parents of children with serious illness. This support may come in the form of emotional (e.g., spending time, expressing affection) or practical (e.g., helping with child care or household tasks) support.^{4,16} Qualitative,¹⁷⁻²⁰ case/control,²¹ and cross-sectional²² studies have suggested that perceived social support may lessen the impact of a child's illness on parents' mental health, and more specifically, research on parents of children with cancer has found that perceived social support may affect parental mood,²¹ stress and coping,^{6,21} levels of psychological distress,^{23,24} and mental health-related functioning.²⁵

The protective association of perceived social support with parental anxiety over time has been empirically tested in

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parents of children with cancer,^{24,25} but not in other diagnosis groups. This raises the question about whether findings from previous studies would also apply to parents of children with other diagnoses.^{26–28} Studies on parents of children with various nonmalignant diseases have highlighted the relationship between social support and psychological outcomes,^{29,30} although these studies have not investigated this relationship over time. In addition, while the long-term effect of social support on parental anxiety has been tested from the point of diagnosis,²⁴ no longitudinal studies have been completed that have studied the relationship between social support and anxiety after an acute medical event, such as a child's hospitalization.

In the following analysis, we tested the hypothesis that a higher perceived social support among parents of children with SLTIs would be associated cross-sectionally and over time with lower levels of anxiety.

Methods

Study design and participants

The participants in this study were parents of seriously ill children in the Decision Making in Serious Pediatric Illness study, a prospective cohort study on parental decision making in the pediatric serious illness context. This study was conducted at the Children's Hospital of Philadelphia (CHOP) from September 2010 to December 2014. CHOP's Institutional Review Board approved the study protocol.

"Parents" included biological, adoptive, or foster parents, and extended family members who were the child's primary decision makers. Parents were eligible for participation if they and their child met the following criteria: the child was a patient at CHOP and had been admitted to the pediatric, neonatal, or cardiac intensive care units, or had been referred to the pediatric advanced care team for palliative care services; the child's attending physician thought that the child had a serious illness and that the parents would likely have to make a major medical decision within the next 12–24 months; the parent was responsible for medical decisions because the child was younger than 18 years or cognitively impaired; and the parents spoke English. Parents were not eligible if the child had died, been discharged, or experienced a nonaccidental injury; or if the parent had lost custody rights. In addition, parents were ineligible if the child's physician deemed the parent to be emotionally overwhelmed or the physician thought the child might die within a month (due to the longitudinal study design; $n=6$, <1% of screened parents).

Parents who consented to participate completed a one-hour in-person interview at baseline (i.e., during the hospital admission), and 20-minute interviews by phone or online at subsequent interviews. Other details about recruitment and study procedures have been reported previously.^{31–33}

Measures

Demographics. Parents completed a baseline demographic questionnaire, which included diagnosis, age, race, ethnicity, educational attainment, and relationship status.

Hospital Anxiety and Depression Scale. Parental anxiety was assessed at baseline, 12, and 24 months with the 14-

item Hospital Anxiety and Depression Scale (HADS),³⁴ which consists of 2 subscales (HADS-Anxiety and HADS-Depression), each of which contain 7-items. Items are rated on a 4-point scale (0–3) with a maximum summated score of 21 for each subscale; higher summated scores indicate higher anxiety/depression levels.³⁵ In our sample, the HADS-Anxiety subscale Cronbach's alpha coefficient was 0.86, consistent with previous studies of caregivers in the palliative care setting.^{36–38}

Social Provisions Scale. Parent-reported social support was assessed at baseline, 12, and 24 months with the Social Provisions Scale (SPS), which is a 24-item, validated measure used in previous research to study respondents' perceptions of social support.^{39–45} The SPS was developed based on the six social provisions identified by Weiss (1974), including guidance (perceived ability to obtain advice or information from others), reliable alliance (perceived ability to rely on others for practical assistance), reassurance of worth (recognition by others of one's competence, skills, and value), social integration (feeling connected to a group that shares similar interests and concerns), attachment (a sense of emotional closeness from which one can derive a sense of security), and opportunity to provide nurturance (a sense that others rely on one for their well-being).^{46,47} Each provision is assessed by four items, and items are scored along a 4-point Likert scale (1 = strongly disagree to 4 = strongly agree). Higher summated scores (across the entire instrument and for each provision) indicate higher perceived levels of social support.^{41,42,48} In our sample, Cronbach's alpha for the total scale was 0.91 and the subscales ranged from 0.56 to 0.78 (Attachment, 0.71; Reassurance of Worth, 0.78; Social Integration, 0.56; Reliable Alliance, 0.56; Guidance, 0.75; Opportunity to Provide Nurturance, 0.63), consistent with previous studies that reported total scale alphas ranging from 0.71 to 0.92^{43,49–53} and subscale alphas from 0.34 to 0.83.^{43,49,53}

Child's perceived health status. Parents were asked to rate their child's current health, with 1 being worst health and 10 being best health.

Statistical analyses

We first described mean SPS and HADS-Anxiety scores at baseline, 12 months, and 24 months. We next performed bivariate linear regressions to test the cross-sectional association between SPS total scores and anxiety scores at baseline, 12 months, and 24 months, as well as the longitudinal association between baseline SPS total scores and anxiety scores at 12 and 24 months. Based on previous literature^{6,21,23–25,54} and the commonly accepted 10% cutoff for change-in-estimate criterion of confounder identification,⁵⁵ we also adjusted for baseline anxiety levels, parent type (i.e., mother, father, other caregiver), parent educational attainment, and child's perceived health. Statistical analyses were performed using the statistical software package Stata/IC 15.1 (StataCorp, College Station, TX), and p -values <0.05 were considered statistically significant.

In additional exploratory analysis, we performed multivariate regression using stepwise backward elimination to determine the most parsimonious model of SPS subscales

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF CHILDREN AND PARENTS AT BASELINE

	N (%)
Children's characteristics (n = 158)	
Age	
1 Year or less	107 (67.7)
2–4 Years	19 (12.0)
5–9 Years	11 (7.0)
10–18 Years	21 (13.3)
Gender	
Female	73 (46.2)
Male	85 (53.8)
Race	
White	118 (74.7)
African American	20 (12.6)
More than one race/other	17 (10.8)
Missing	3 (1.9)
Ethnicity	
Non-Hispanic	137 (86.7)
Hispanic	19 (12.0)
Missing	2 (1.3)
Primary complex chronic condition (Note: not mutually exclusive; thus, the % does not sum to 100%)	
Cardiovascular	77 (48.7)
Respiratory	89 (56.3)
Congenital or genetic	111 (70.3)
Neuromuscular	63 (39.9)
Metabolic	17 (10.8)
Malignancy	15 (9.5)
Renal	16 (10.1)
Other	53 (33.5)
Parents' characteristics (n = 200)	
Parent type	
Mother	136 (68)
Father	60 (30)
Other	4 (2)
Age	
Mean/SD	33.7 (7.92)
Missing	1
Race	
White	161 (80.5)
African American	22 (11.0)
More than one race/other	15 (7.5)
Missing	2 (1.0)
Ethnicity	
Non-Hispanic	180 (90)
Hispanic	17 (8.5)
Missing	3 (1.5)
Highest education level completed	
High school/general educational development	33 (16.5)
Trade/technical/vocational	8 (4.0)
College/graduate school	159 (79.5)
Relationship status	
Married/partnered	171 (85.5)
Separated/divorced/widowed	6 (3.0)
Single	23 (11.5)
No. of other children	
0	66 (33.0)
1–4	123 (61.5)
5+	10 (5.0)
Missing	1 (0.5)

(continued)

TABLE 1. (CONTINUED)

	N (%)
Employment status	
Full-time	99 (49.5)
Part-time	23 (11.5)
Not employed/looking for employment	34 (17.0)
Homemaker	42 (21.0)
Retired	2 (1.0)

Unless otherwise noted, cell entries are percentages. Percentages are within each demographic or clinical characteristic variable, and include missing data if present.
SD, standard deviation.

that predict anxiety scores at baseline, 12 months, and 24 months. In brief, we began with the full model of all subscales and covariates, and sequentially eliminated subscales at each step with a *p*-value ≥ 0.2 , which is the level-of-stay significance recommended for small datasets.⁵⁶

Due to the patient population (i.e., children with serious illnesses) and the longitudinal study design, some participants were, inevitably, lost to follow-up. Restricting the analysis to complete cases (i.e., parents who had responses to all variables) using listwise deletion would reduce the sample from 200 to 83 parents, resulting in significant loss of statistical power, larger standard errors (SEs), and wider confidence intervals.⁵⁷ Because of limitations of complete case analysis,^{58,59} we used multiple imputation to generate sets of plausible estimates of missing values.^{57,58} Multiple imputation is a flexible, simulation-based statistical technique⁵⁷ that has been used to address missing data in previous palliative care research.^{59–61} We performed multiple imputation using chained equations (MICE) to generate *M* = 20 imputed datasets following a linear regression model.⁵⁷ Overall, 7.6–8.3% of cases were imputed across variables.

Finally, we conducted logistic regression modeling to assess whether there were any associations between demographic or social support variables and nonparticipation or attrition.

Results

Description of sample

Of 295 parents approached, 95 parents declined to participate (67.8% participation rate). Our sample consisted of 200 parents (of 158 children) (Table 1) who completed the baseline interview, 113 (of 90 children) who completed the 12-month interview, and 97 (of 77 children) who completed the 24-month interview.

The average total SPS score at baseline was 87.5 (SE 0.57) out of 96 possible points (Table 2). This mean score decreased to 76.7 (SE 0.93) at 12 months, and increased to 83.0 (SE 1.06) at 24 months (Table 2). The differences between baseline SPS scores and 12-month ($F_{1,66} = 146.0$; $p < 0.01$) and 24-month ($F_{1,88} = 23.0$; $p < 0.01$) SPS scores were statistically significant. Average SPS subscale scores ranged from 13.9 for Social Integration to 15.3 for Reliable Alliance (out of 16 possible points) at the baseline interview. These scores followed a similar pattern to the SPS total scores over time, dipping at 12 months (lowest score: Attachment 11.6; highest score: Reassurance of worth 13.6) and rebounding at 24 months (lowest score: Social integration 13.1; highest score: Reliable alliance 14.5) (Table 2).

TABLE 2. DESCRIPTIVE STATISTICS OF STUDY MEASURES ACROSS TIME POINTS

Study measure	Baseline visit (N=200)	12-Month visit (N=113)	24-Month visit (N=97)
	M (SE)	M (SE)	M (SE)
SPS total score (24–96)	87.5 (0.57)	76.7 (0.93)	83.0 (1.06)
SPS subscale scores (4–16)			
Guidance	14.9 (0.14)	13.4 (0.20)	14.1 (0.23)
Reliance alliance	15.3 (0.10)	13.1 (0.19)	14.5 (0.20)
Reassurance of worth	14.0 (0.13)	13.6 (0.22)	13.4 (0.21)
Social integration	13.9 (0.12)	12.0 (0.16)	13.1 (0.21)
Attachment	14.8 (0.13)	11.6 (0.23)	13.8 (0.24)
Opportunity to provide nurturance	14.6 (0.11)	13.0 (0.18)	14.1 (0.19)
HADS-Anxiety (0–21)	10.0 (0.32)	8.4 (0.41)	8.4 (0.44)

HADS, Hospital Anxiety and Depression Scale; SE, standard error; SPS, Social Provisions Scale.

The average HADS-Anxiety score at baseline was 10.0 (SE 0.32) out of 21 possible points. This mean score decreased to 8.4 (SE 0.41) at 12 months and remained at 8.4 (SE 0.44) at 24 months (Table 2). Differences between baseline and 12-month ($F_{1,92}=7.3$; $p<0.01$) and 24-month ($F_{1,91}=10.1$; $p<0.01$) anxiety levels were statistically significant.

Cross-sectional association between total SPS scores and HADS-Anxiety

Cross-sectionally, total SPS scores were negatively associated with HADS-Anxiety scores at baseline ($B=-0.10$, $p<0.01$, 95% CI=-0.17 to -0.03), 12 months ($B=-0.13$, $p=0.03$; 95% CI=-0.24 to -0.01), and 24 months ($B=-0.19$, $p<0.01$; 95% CI=-0.25 to -0.12) (Fig. 1). After adjusting for parent role, parent education, and child's perceived health, total SPS scores remained negatively associated with HADS-Anxiety scores at each interview (Table 3, top portion). The adjusted estimates represent small-to-medium effect sizes of SPS scores on HADS-Anxiety scores.

Longitudinal association between baseline SPS scores and subsequent HADS-Anxiety

Longitudinally, baseline SPS scores were associated with HADS-Anxiety scores at each follow-up interview. Higher

baseline SPS scores remained negatively associated with lower HADS-Anxiety scores at 12 months ($B=-0.12$, $p=0.03$; 95% CI=-0.23 to -0.01) and 24 months ($B=-0.11$, $p=0.04$; 95% CI=-0.21 to -0.01) (Fig. 2). In the adjusted models, this association was present at 12 months ($p=0.06$) with a small-to-medium effect size, but had dissipated by 24 months ($p=0.78$) (Table 3, bottom portion).

Additional exploratory analysis

To examine which aspect of social support was most strongly associated with subsequent anxiety levels, we implemented backward stepwise elimination in a multivariable regression model, accounting for baseline anxiety levels, parent type, parent education, and child's perceived health, to determine the most parsimonious combination of subscales to predict anxiety. The correlation between SPS subscales in this sample is displayed in Supplementary Table S1. After sequentially removing each subscale with a p -value of ≥ 0.2 ,⁵⁶ we retained the Social Integration subscale at baseline ($p<0.01$), at 12 months ($p=0.02$), and at 24 months ($p=0.03$) (Supplementary Table S2).

Finally, using logistic regression modeling, we identified only weak, statistically nonsignificant, and inconsistent associations between participant characteristics and missingness over time (analysis not shown).

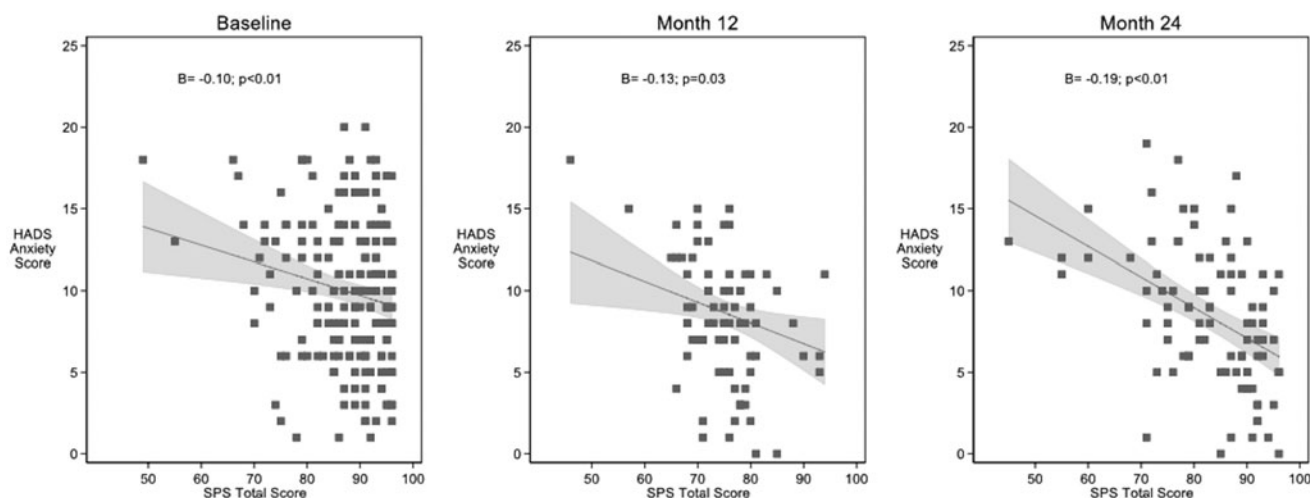


FIG. 1. Cross-sectional association of perceived social support with anxiety at each time point.

TABLE 3. ADJUSTED MODELS OF PERCEIVED SOCIAL SUPPORT AND ANXIETY

Time (N)	Covariates	B	95% CI	p	
Cross-sectional	Baseline (200)	(intercept)	23.4	<0.01	
		SPS total	-0.1	-0.21 to -0.05	<0.01
		Parent role (dad)	-1.3	-2.56 to 0.06	0.06
		Parent role (other)	-0.2	-4.60 to 4.20	0.92
		Parent education	0.1	-0.24 to 0.52	0.48
		Child's perceived health	-0.4	-0.61 to -0.13	<0.01
	12 Months (113)	(intercept)	22.7	<0.01	
		SPS total	-0.1	-0.24 to -0.02	0.03
		Parent role (dad)	-0.9	-2.55 to 0.78	0.30
		Parent role (other)	1.6	-2.43 to 5.60	0.43
		Parent education	-0.1	-0.60 to 0.49	0.85
		Child's perceived health	-0.6	-1.00 to -0.09	0.02
	24 Months (97)	(intercept)	26.2	<0.01	
		SPS total	-0.2	-0.22 to -0.09	<0.01
	Parent role (dad)	-2.1	-3.30 to -0.87	<0.01	
	Parent role (other)	Omitted		N/A	
	Parent education	0.2	-0.33 to 0.65	0.52	
	Child's perceived health	-0.6	-1.00 to -0.26	<0.01	
Longitudinal	12 Months (113)	(intercept)	18.5	<0.01	
		SPS total at baseline	-0.1	-0.20 to -0.01	0.06
		Anxiety at baseline	0.2	0.05 to 0.41	0.01
		Parent type (dad)	-0.3	-1.90 to 1.30	0.73
		Parent type (other)	0.6	-4.20 to 5.40	0.80
		Parent education	0.1	-0.48 to 0.69	0.72
		Child's perceived health	-0.5	-0.98 to -0.08	0.02
	24 Months (97)	(intercept)	11.0	<0.01	
		SPS total at baseline	-0.01	-0.09 to 0.07	0.78
		Anxiety at baseline	0.5	0.32 to 0.62	<0.01
		Parent type (dad)	-0.9	-2.30 to 0.44	0.18
		Parent type (other)	Omitted		N/A
		Parent education	0.1	-0.36 to 0.54	0.68
		Child's perceived health	-0.8	-1.20 to -0.51	<0.01

Discussion

Among parents of children with primarily nononcologic SLTIs over a two-year period, we found that higher levels of perceived social support were associated with lower levels of

anxiety in both the cross-sectional and longitudinal models. Specifically, the Social Integration subscale from the SPS appeared to be most consistently predictive of anxiety levels over time. This longitudinal association between perceived social support at baseline and subsequent levels of anxiety

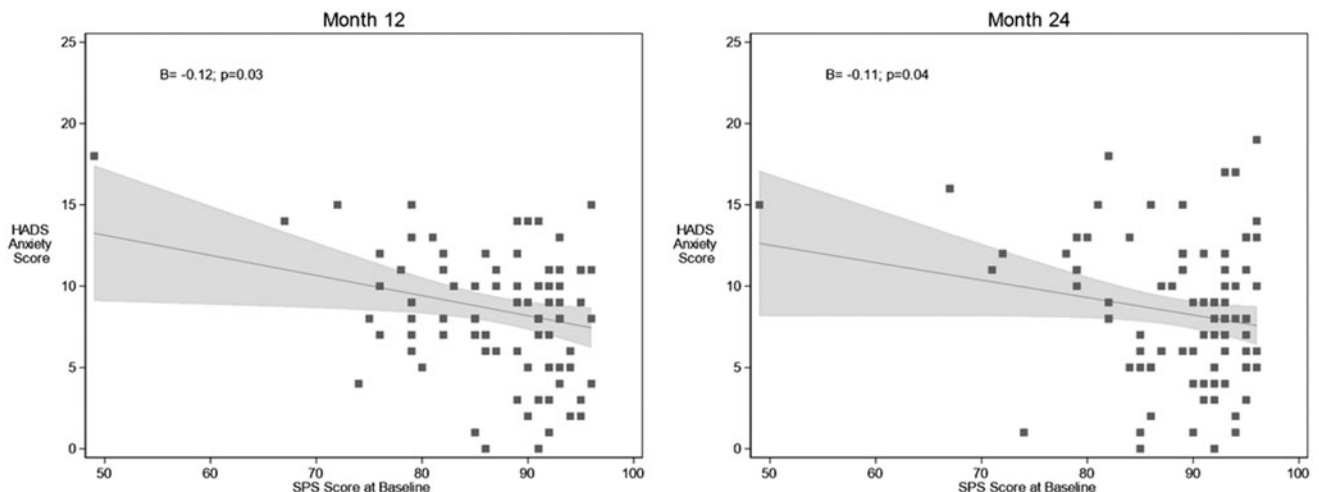


FIG. 2. Longitudinal association of perceived social support at baseline with anxiety at 12 and 24 months.

was present a year later, even when accounting for baseline levels of anxiety, as well as parent type, parent education, and child's perceived health, before dissipating by 24 months. Finally, in this sample, the association between perceived social support and anxiety occurred in the context where both anxiety and social support scores decreased significantly in the 12 months following hospitalization.

Our observation of a statistically significant, medium-to-small-sized inverse association between social support and parental anxiety, both cross-sectionally and longitudinally, is consistent with, and extends beyond, previous studies. Qualitative studies have found that while parents sometimes felt isolated from their social network, parents identified social support as critical for coping with the emotional stress of parenting a seriously ill child.¹⁷⁻²⁰ One cross-sectional case/control study of parents of children with cancer found that poor social support was the most important factor linked with poor mental health outcomes.²¹

Our two-year study time frame allowed us to examine the temporal relationship between social support and anxiety, affirming our hypothesis that social support has a protective association on parental anxiety over time. A study of 163 mothers of children with cancer also observed an inverse relationship between social support at the time of their child's hospitalization for stem cell transplantation and mothers' mental health-related functioning in the subsequent year.²⁵ A five-year study of 94 parents of children with cancer, conversely, found that social support variables explained a proportion of the psychological distress for fathers five years after diagnosis, but not for mothers.²⁴ This study, however, examined overall satisfaction with social support and quantity of positive/negative social interactions; our study used the SPS, which examined specific dimensions of social support. This study also focused on the oncology setting, whereas our study included a large sample of parents of children with nonmalignant SLTIs. Parents of children with nonmalignant diseases in previous studies had longer caregiving trajectories, greater unmet needs, fewer social support resources, and higher self-rated poorer overall health,²⁶ in addition to less developed, accessible, and flexible health care services²⁷ compared with families of children with malignant disease. Finally, while the association between social support and anxiety dissipated by 24 months in our adjusted modeling, this finding was not unexpected given that social support may be a dynamic, rather than fixed, attribute.

Beyond providing much firmer evidence of the association between perceived social support and parental anxiety, this study also has three other findings that warrant discussion. First, we observed that anxiety scores decreased significantly from baseline to 12 months, and were stable from 12 until 24 months. This decrease over time is consistent with previous studies, which found that parental anxiety and distress levels peak at the time of the child's diagnosis and trended downward to near-normative levels at 6,²³ 12,²⁵ and 20⁶² months, and as far out as five years.²⁴ Our analysis examined anxiety levels after an acute medical event (i.e., hospitalization), regardless of time since diagnosis. Anxiety levels likely spike during hospitalization, subsiding to more normal levels afterward. Future studies are needed to better understand fluctuations in parents' anxiety from a child's diagnosis through the course of illness, particularly surrounding acute medical events such as hospitalizations.

Second, we noted a significant decrease in perceived social support levels over time, particularly from baseline to 12 months, which is consistent with previous studies. One study of 94 parents of children with cancer found that the amount of perceived support peaked at diagnosis (which the authors termed "crisis support") and declined during the first year, stabilizing at a fairly constant level through five years.²⁴ Qualitative studies have observed that parents' social support networks may shrink,⁶³ and parents may feel "forgotten,"¹⁸ as time passes after their child's diagnosis. Our findings indicate that, similar to social support following a diagnosis, "crisis" levels of social support may increase during hospitalization and decrease in the subsequent year.

Third, our analysis examined the specific dimensions of social support, which may provide a more nuanced understanding of how social support impacts parental anxiety. In particular, we found that the Social Integration subscale, which relates to the feeling of being connected to others who have similar interests, concerns, and shared experiences,⁶⁴ was significantly associated with lower parental anxiety across time. Feeling connected to a network of family, friends, or other parents of ill children may be important for coping and adjustment to a child's diagnosis and treatment.^{28,63,65,66} Greater understanding of the concept of social integration may be important for understanding the impact of social support on parental anxiety, and how clinicians could best intervene to improve parental mental health outcomes during the course of their child's illness.

Our findings should be interpreted with four main limitations in mind. First, we recognize that while we observed an association between perceived social support and parental anxiety, we cannot infer causation. Second, the parent sample was demographically homogeneous, limiting generalizability. Third, we used multiple imputation to address missing data. We did not find a consistent pattern of missingness in participants over time, but the possibility that data were not missing entirely at random could not be ruled out.^{24,62} Fourth, we did not account for family-level factors (e.g., family cohesion) or personal factors (e.g., coping style or prior traumatic life events), which have been associated with parental distress and posttraumatic stress disorder (PTSD) symptomatology in pediatric oncology research.^{14,66}

Despite these limitations, the results of this study suggest that clinicians might support parents by helping them tap into various forms of social support. For example, clinicians could help parents identify additional sources of support, particularly in the year following an acute medical event when parents may experience a significant decline in "crisis" levels of social support. Clinicians could connect parents with networks of other parents of children with similar illnesses, where parents may feel a natural sense of connectedness due to shared experiences.⁶³ Future intervention-based research, however, is greatly needed in this area.

In conclusion, our analysis suggests that higher levels of social support are associated with lower levels of parental anxiety after an acute event, such as hospitalization, in parents of children with serious illnesses. While more work is needed to understand how to optimize support over time for different groups of parents (particularly those of children with nonmalignant disease), clinicians should work with all parents to develop strategies for addressing social support needs, particularly following an acute medical event.

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Table S1

Supplementary Table S2

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