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## Quality of Life Among Pediatric Patients With Cancer: Contributions of Time Since Diagnosis and Parental Chronic Stress

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### Abstract

**Background**—Pediatric cancer is associated with a host of negative psychosocial consequences; however, outcomes vary extensively suggesting a need to better understand this variation.

Empirical research suggests a positive association between time since diagnosis (TSD) and Quality of Life (QoL). In addition to TSD, family stressors have been found to be particularly important in predicting QoL among children. The current study examined parental chronic stress beyond TSD in explanation of QoL functioning among a sample of pediatric patients with cancer.

**Procedure**—Participants included 43 pediatric patients aged 5–18 years ( $M_{\text{age}} = 10.2 \pm 3.6$ ) who were undergoing oncological treatment. Parents reported on TSD, child's QoL, and their own chronic stress.

**Results**—TSD was associated with greater physical functioning ( $r = 0.30, P < 0.05$ ). Parental chronic stress was associated with poorer emotional ( $r = -0.54, P < 0.01$ ), physical ( $r = -0.41, P < 0.01$ ), and social functioning ( $r = -0.44, P < 0.01$ ). Further, hierarchal linear regression analyzes indicated parental chronic stress contributed incrementally beyond TSD in the explanation of physical ( $\beta = -0.37, t = -2.58, P < 0.01$ ), emotional ( $\beta = -0.47, t = -3.51, P < 0.00$ ), and social functioning ( $\beta = -0.38, t = -2.67, P < 0.01$ ).

**Conclusions**—Parental chronic stress is associated with reduced levels of emotional, physical, and social functioning among pediatric patients. Future research is needed to further investigate the process by which chronic stress within the family interferes with adaptive coping among pediatric patients. In addition, clinical services may benefit from increased consideration of family factors, such as parental chronic stress, during oncological treatment.

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## Keywords

chronic stress; parental stress; pediatric cancer; quality of life; time since diagnosis

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## INTRODUCTION

The incidence of pediatric cancers has steadily increased since 1975 by 0.6% per year [1]. Experts agree that contributions of an increase in medical advancement and interventions leading to early diagnosis as well as changes in environmental factors (e.g., exposure to radiation and environmental chemicals) are likely the best explanations for this increase [1]. Fortunately, the rate of mortality following diagnosis has significantly decreased; in the period from 1975 to 2000, the mortality rate declined more than 50% [1]. This increase in survivorship is encouraging and indicates that children and their families now have a longer period in which to socially and emotionally cope with a cancer diagnosis. A better understanding of the various psychosocial problems these children experience following diagnosis is critical as pediatric patients with cancer can display psychological and social maladjustment [2], compromised school attainment, and academic achievement [3,4]. However, these outcomes, which are often referred to as Quality of Life (QoL) variables, vary extensively among patients, suggesting a need to better understand this variation.

QoL refers to both the level of physical and psychological functioning within an individual. QoL in childhood is conceptualized by level of functioning among emotional, physical, school, and social domains. For pediatric patients with cancer, QoL is an important consideration used to gauge the child's overall physical and mental health during and following treatment. Whereas previous research has reported emotional distress in the form of depression or anxiety for pediatric patients newly diagnosed with cancer to be relatively rare [5], patients do tend to experience reduced QoL. Children undergoing oncological treatment experience significant impairment of QoL when compared with patients out of treatment [6], and among healthy populations [7]. Pediatric cancer patients also experience diminished physical, social, and emotional functioning as compared to community samples [6,8,9], but specific domains of functioning are not well understood and previous research has revealed mixed findings. Due to the wide variety of potential variables that could uniquely influence QoL across various domains of functioning, research has often examined treatment-level variables in the prediction of QoL for pediatric patients with cancer. Of these, time since diagnosis (TSD) is widely understood to be an important treatment-level variable in prediction of pediatric QoL, as certain symptoms are known to either increase or decrease over the course of time [10].

Pediatric patients with cancer currently undergoing treatment experience decreased QoL during and throughout the year following treatment, while those who have been out of treatment for over a year experience improved QoL [6,8]. Other studies suggest this pattern continues over time [10,11]. For example, Landolt et al. [8] found that children with newly diagnosed cancer experienced significant declines in QoL in the physical and emotional functioning domains, but not in the social functioning domain, at 6 weeks after diagnosis. At the 1-year follow-up, patients reported improvements in physical functioning and

developmentally typical levels of social functioning, but emotional functioning was still reduced [8]. Smith et al. [6] found that within the first year of treatment, the greatest deficits of QoL were in emotional, physical, and social functioning. Research also indicates that the relationship between treatment-level factors (including TSD) and QoL decreases over time [6]. Therefore, it is important to consider other factors beyond TSD in the examination of QoL. One consideration is family-level factors, as parents can influence the QoL experienced by their children [12]. Studies suggest that the health and well-being of the child is inextricably linked to the well-being of their parents [13], and chronic parental stress may play an important role in the relationship between TSD and QoL.

Parental chronic stress refers to the daily and persistent problems faced by parents or caregivers. Stressors that reoccur or endure over time are considered chronic, and these stressors are understood to build and compound, ultimately leading to distress and exhaustion [14]. The overall level of family functioning is central to childhood development and coping for pediatric patients [12,15], and the presence of chronic stress leads to a variety of interrelated problems within family functioning. For example, better parent adjustment 6 weeks after cancer diagnosis is associated with improved pediatric QoL [8]. However, parents of children with cancer often experience high levels of stress, leading to families becoming less cohesive and more conflicted [16,17]. Family functioning and support for pediatric patients is a vital resource that can promote improvement of pediatric QoL both during and after treatment [15].

Similar to treatment-related factors, specific relationships among QoL domains are not well understood with regard to family-level factors. Previous research often considers QoL as a single dimension when investigating family-level factors [18]. When not examined as a single, unitary dimension, QoL has been assessed as physical versus psychosocial functioning as a whole [19]. However, the lack of distinction among specific psychosocial domains obscures potential differences across subdomains of functioning. Further, explicit consideration of the role parental chronic stress has beyond TSD is needed to understand QoL domains of functioning among pediatric patients with cancer. It is therefore critical to investigate explanations of QoL examining both TSD and parental chronic stress among pediatric patients undergoing oncology treatment that may be meaningful in helping children adjust and thrive following their cancer diagnosis.

## CURRENT STUDY

The current study examined parental chronic stress beyond TSD in the explanation of QoL among a sample of pediatric patients with cancer. Our overarching model driving our hypothesis examines the contributors to QoL by incorporating both treatment-level and familial-level processes. Specifically, the model takes into consideration the way in which TSD and parental chronic stress work together with regard to varying quality of life trajectories. Drawing from the literature on treatment-level variables [6,8], it was hypothesized that pediatric patients with greater time since cancer diagnosis would report better QoL including emotional, physical, school, and social functioning. Further, given the importance of family-level variables [12,15], it was hypothesized that parental chronic stress would contribute incrementally above and beyond TSD in predicting QoL. Specifically,

parental chronic stress was expected to be negatively associated with emotional, physical, and social functioning after accounting for TSD for pediatric patients. Given the relative lack of empirical findings regarding parenting factors and school functioning among pediatric patients with cancer, and literature suggesting parental involvement may have little to no impact on children's academic success [20], parental chronic stress was not expected to be associated with school functioning.

## METHODS

### Participants

Participants included 43 pediatric patients aged 6–18 years ( $M_{\text{age}} = 10.2$ ,  $SD = 3.6$ ) currently undergoing treatment for a cancer diagnosis at a large university medical center in the Southern United States. Table I shows demographic data. All data were collected from Winter 2009 to Fall 2010. Well over half of the sample (77%) was male, and more than half were White/Caucasian (57%). The majority (86%) of caregiver respondents were patients' biological parents, and 79% of caregivers were mothers. As such, primary caregivers and biological parents are both referred to as parents throughout. The sample was heterogeneous in terms of type of cancer diagnosis with the most common form of cancer being Acute Lymphoblastic Leukemia (40%). Participants came from relatively impoverished families with 19% of respondents reporting a total combined household income of under \$15,000 per year, and 21% reporting a total combined household income of \$15,000-\$35,000 per year. For purposes of analyzes, total household income was divided into two groups: below \$35,000 (45%) and above \$35,000 (55%).

### Procedure

All study procedures were approved by the medical center's Institutional Review Board. Patients were recruited to participate based on a known cancer diagnosis, regardless of type of cancer and severity, during regularly scheduled oncology visits. Parents provided informed consent before completing the questionnaire packet. One parent per patient was included, and all families seen in the clinic were invited to participate.

### Measures

**Time since diagnosis**—Parents reported on TSD. TSD ranged from 1 to 53 months, of which, over half (58.1%) of the patients had been diagnosed within the past 12 months.

**Parental chronic stress**—The Everyday Stressors Index (ESI) [21] is a 20-item scale designed to assess level of chronic stress as rated by the parent. For example, items included “Owing money” and “Problems getting along with your family.” Parental chronic stress was rated on a four point Likert-type rating scale ranging from 1 (*Not at all bothered*) to 4 (*Bothered a great deal*). The ESI has been shown to demonstrate good external and internal validity [22]. In the current sample, this scale demonstrated good internal consistency with a Cronbach's coefficient  $\alpha$  of 0.83.

**Quality of life**—The Pediatric Quality of Life Inventory (PedsQL) [23] is a 23-item parental-report measure designed to assess QoL among pediatric patients. Parents rate their

children on four scales of QoL, including Emotional Functioning (e.g., “worrying about what will happen to him or her”), Physical Functioning (e.g., “having hurts or aches”), School Functioning (e.g., “keeping up with schoolwork”), and Social Functioning (e.g., “getting along with other children”). QoL was rated on a five point Likert-type rating scale ranging from 1 (*Never*) to 5 (*Almost Always*) with lower scores indicating better QoL. The PedsQL has been shown to demonstrate good external and internal validity [23]. In the current sample, this scale demonstrated good to excellent internal consistency with Cronbach’s coefficient  $\alpha$ ’s of 0.72 (emotional), 0.96 (physical), 0.74 (school), and 0.77 (social).

## Analyses

As noted above, the PedsQL is scored such that lower scores indicate better QoL. For ease of interpretation, we reverse-coded PedsQL scales in our analyzes so that higher scores indicate better QoL. Rates of cancer type were too low to examine unique types. As such, we created a dichotomous variable, acute lymphoblastic leukemia (ALL) (1) and all other types combined (0). First, bivariate zero-order correlations for all study variables were examined in order to understand their linear relationship. Next, to examine both the unique and incremental contribution of TSD and parental chronic stress in the prediction of each QoL domain of functioning, we performed four separate hierarchical linear regression analyzes in the explanation of each of the QoL domains. Specifically, demographic variables that evidenced significant bivariate correlations were included as covariates in Step 1. TSD was then entered in Step 2 and parental chronic stress was entered into the final step to examine the unique and incremental contribution beyond TSD.

## RESULTS

### Bivariate Correlations Among Study Variables

As shown in Table II, age was associated with poorer emotional ( $r = -0.35, P < 0.05$ ) and social functioning ( $r = -0.39, P < 0.05$ ). Neither gender nor total household income was significantly associated with any of the QoL domains. Contrary to previous findings [6,8,9], TSD was only associated with greater physical functioning ( $r = 0.30, P < 0.05$ ). TSD was also associated with the diagnosis of ALL ( $r = 0.43, P < 0.01$ ). As expected, greater levels of parental chronic stress was associated with poorer emotional ( $r = -0.54, P < 0.01$ ), physical ( $r = -0.41, P < 0.01$ ), and social functioning ( $r = -0.44, P < 0.01$ ), but was unrelated to school functioning.

### Predicting QoL From TSD and Parental Chronic Stress

As shown in Table III, results of the hierarchical linear regression analyzes suggest that age was associated with both emotional ( $\beta = -0.35, t = -2.38, P < 0.05$ ) and social functioning ( $\beta = -0.38, t = -2.69, P < 0.01$ ), significantly explaining 12 and 15% of the variance, respectively. TSD contributed a significant 9% of the variance in physical functioning ( $\beta = 0.30, t = 2.04, P < 0.05$ ), but was not associated with emotional, school, or social functioning. Parental chronic stress contributed an incremental 20% of the variance in emotional functioning, 13% in physical functioning, and 13% in social functioning after accounting for age and TSD. Specifically, greater levels of parental chronic stress was

significantly associated with lower levels of physical functioning ( $\beta = -0.37$ ,  $t = -2.58$ ,  $P < 0.01$ ) incrementally beyond TSD, and lower levels of emotional ( $\beta = -0.47$ ,  $t = -3.51$ ,  $P < 0.00$ ) and social functioning ( $\beta = -0.38$ ,  $t = -2.67$ ,  $P < 0.01$ ) incrementally beyond both age and TSD. Parental chronic stress was not associated with school functioning. Overall, the full models accounted for 35, 22, and 28% of the total variance in emotional, physical, and social functioning, respectively.

## DISCUSSION

Elucidating both treatment- and family-level influences associated with QoL for pediatric patients with cancer is critical as QoL has implications immediately following diagnosis and continuing throughout the patient's lifetime [6,8,10,11]. Additionally, understanding the potentially differing correlates of various QoL domains of functioning is imperative to more wholly understanding the unique development of various psychosocial and behavioral outcomes among this population. Pediatric patients with cancer undergoing treatment are at an increased risk for low QoL [6], due to both their immediate treatment experiences as well as familial influences. The current study represents the first investigation to date on the importance of both family- and treatment-level variables in the explanation of QoL functioning among pediatric patients with cancer.

Contrary to expectations, TSD was only associated with QoL in the form of low physical functioning. Whereas, we expected significant associations across all domains of functioning, TSD was not associated with emotional, school, or social functioning at the bivariate level. These results are contrary to previous findings suggesting that pediatric patients experience reduced QoL in the immediate stages of oncological treatment and improved QoL as time progresses [6,8,10,11]. One potential explanation may be that treatment initially has a substantial impact on physical functioning [24], and thus physical functioning is the most evident QoL domain of functioning. Further, our limited sample size may have been too small to detect effects. Future research is needed to explicitly examine the role of TSD on each specific QoL domain of functioning for pediatric patients undergoing oncological treatment.

Consistent with expectations, parental chronic stress uniquely predicted 13% of physical functioning above and beyond TSD. Additionally, parental chronic stress uniquely predicted 20% of emotional functioning and 13% of social functioning above and beyond both age and TSD. Specifically, higher levels of parental chronic stress predicted lower levels of emotional, physical, and social functioning. As expected, parental chronic stress was not associated with school functioning. Previous research found that pediatric patients between 15 and 17 years old with cancer were at the greatest risk for low school functioning [6]. The relatively large age range of patients in the current study, in addition to the relatively younger age of our sample ( $M_{\text{age}} = 10.2$  years), may have contributed to these null findings. Additionally, others have reported school and/or work functioning deficits among survivors of cancer, rather than those undergoing treatment [3,4]. Taken together, these findings provide additional support to the notion that chronic stress experienced by parents may be associated with direct, harmful effects on QoL of pediatric patients with cancer, specifically within the domains of emotional, physical, and social functioning. Further, these results



indicate that treatment plans should include assessment of parental chronic stress and provision of coping strategies and/or resources (e.g., transportation vouchers, assistance with obtaining food, or finding quality childcare for siblings) for impacted parents. Care coordination teams may be particularly important in this regard. Care coordination is a model that seeks to organize and promote effective communication across multidisciplinary teams that include, for example, oncologists, social workers, psychologists, and community programs. The US Department of Health and Human Services has found that utilization of care coordination teams improve outcomes for all involved with patients, including their families [25].

Further, although clinicians are likely to attend to the psychosocial aspect of the child, it is important to also consider psychosocial aspects of parents. Opportunities to address these are plentiful, for example, during the history assessment and physical examinations during clinic visits. If chronic parental stress is identified, parents should be offered psychological counseling and a referral to social services to help them cope with their stress. In accordance with care coordination teams, referrals to social workers and social services can provide an avenue to help families acquire appropriate services.

This study is not without limitations. Due to the cross-sectional and correlational nature of our data, causal conclusions are not possible. It is important for future research to examine and replicate the directionality of these relationships using prospective designs. Additionally, all measures were reported by parents. While research suggests proxy reports from parents and other caregivers to be reliable and comparable to pediatric patient self-reports in assessing QoL [19], other research has found parent reporting to be less reliable than self-reports where parents tend to underestimate QoL [26]. Additionally, due to the confidential nature of the study, we were unable to confirm parent report of TSD against patient medical records. Finally, due to our relatively small sample size, we were not able to explore interaction effects due to limited power and we were not able to explore potential differences among cancer diagnoses. Although we did not find an association between our dichotomous type of cancer variable and QoL, future research should further investigate these relationships in larger samples.

Although we predicted treatment-level variables, like TSD, to predict QoL in pediatric patients with cancer, it was the incremental contribution of a family-level variable (parental chronic stress) that was the strongest predictor of emotional, physical, and social functioning. These findings provide important insight into the psychosocial and physical functioning of pediatric patients with cancer, and indicate that consideration of family-factors, such as chronic stress, are important to consider in treatment and care practices from diagnosis and treatment through remission.

## Abbreviations

<b>ALL</b>	acute lymphoblastic leukemia
<b>QoL</b>	quality of life
<b>TSD</b>	time since diagnosis

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TABLE I

## Demographic Data

	N	%
Gender		
Male	33	76.7
Female	10	23.3
Race		
Black/African American	18	41.9
White/Caucasian	25	58.1
Age		
5–11	29	62.8
12–18	14	37.2
Type of cancer		
Acute Lymphoblastic Leukemia (ALL)	17	39.5
Other	26	60.5
Biological parent		
No	6	14.0
Yes	37	86.0
Relation to child		
Mother	34	79.1
Father	3	7.0
Other (e.g., guardian)	6	14.0

N = 43.

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TABLE II

## Bivariate Correlations Among Study Variables

	1	2	3	4	5	6	7	8	9	10
1. Age										
2. Gender (0 = Male, 1 = Female)	-0.19									
3. Time since diagnosis	-0.15	-0.02								
4. Household income	-0.04	-0.10	0.29							
5. ALL Dichotomous (0 = Other, 1 = ALL)	-0.27	0.02	<b>0.43<sup>b</sup></b>	0.08						
6. Parental chronic stress	0.24	-0.02	-0.21	-0.12	-0.02	<b>0.83</b>				
Quality of life										
7. Emotional functioning	-0.35 <sup>a</sup>	0.11	0.23	0.17	0.13	-0.54 <sup>b</sup>	<b>0.72</b>			
8. Physical functioning	-0.29	-0.19	<b>0.30<sup>a</sup></b>	0.18	-0.02	-0.41 <sup>b</sup>	-0.63 <sup>b</sup>	<b>0.96</b>		
9. School functioning	-0.19	0.26	0.28	-0.07	-0.00	-0.23	-0.30 <sup>a</sup>	-0.33 <sup>a</sup>	<b>0.74</b>	
10. Social functioning	-0.39 <sup>a</sup>	0.11	0.04	0.03	-0.14	-0.44 <sup>b</sup>	-0.28	-0.49 <sup>b</sup>	-0.46 <sup>b</sup>	<b>0.77</b>
Mean	10.16	-	14.13	-	-	35.94	13.17	23.79	13.08	10.98
Standard deviation	3.63	-	13.80	-	-	9.25	3.76	9.23	3.89	4.19
Range	5-18	-	1-53	-	-	22-63	5-25	8-40	5-22	5-21

N = 43. Scale reliabilities (Coefficient a) are shown in boldfaced italics on the diagonal.

<sup>a</sup>Correlation is significant at the 0.05 level (two-tailed).

<sup>b</sup>Correlation is significant at the 0.01 level (two-tailed). Point biserial correlations were performed for categorical × continuous variables.

Predicting Quality of Life Functioning From Time Since Diagnosis and Parental Chronic Stress

TABLE III

	Emotional			Physical			School			Social		
	$R^2$	$\beta$	t	$R^2$	$\beta$	t	$R^2$	$\beta$	t	$R^2$	$\beta$	t
Age	0.15*	-0.35	-2.38*	-	-	-	-	-	-	0.15**	-0.39	-2.69**
$R^2/\Delta R^2$	0.05			0.09*			0.08			0.00		
Time since diagnosis		0.18	1.24	0.30	2.06*		0.28	1.90		-0.01	-0.09	
$\Delta R^2$	0.22**			0.13*			0.03			0.13**		
Parental stress		-0.47	-3.51**	-0.37	-2.58**		-0.18	-1.20		-0.38	-2.67**	

N = 43. Parental Stress = Parental Chronic Stress. *Emotional Functioning*:  $F$ -test of change from Step 1 to Step 2:  $F = 6.00$ ,  $df = 41$ ; Step 2 to Step 3:  $F = 11.81$ ,  $df = 40$ . *Physical Functioning*:  $F$ -test of change from Step 2 to Step 3:  $F = 7.41$ ,  $df = 41$ . *Social Functioning*:  $F$ -test of change from Step 1 to Step 2:  $F = 6.74$ ,  $df = 41$ ; Step 2 to Step 3:  $F = 5.67$ ,  $df = 40$ .

\*  $P < 0.05$ ,

\*\*  $P < 0.01$ .