

Impact of Sociodemographic Factors, Stress, and Communication on Quality of Life in Survivors of Pediatric Cancer

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August 2, 2023

Abstract

Background: While most research has largely focused on medical risks associated with reduced quality of life (QOL) in survivors, sociodemographic and family factors may also play a role. Thus, we examined sociodemographic factors and family factors associated with survivor QOL, including adolescent's cancer-specific stress, mother's general stress, and mother-adolescent communication. **Methods:** Mothers ($N=80$) and survivors (ages 10-23, $N=50$) were assessed 5 years following initial diagnosis. Mothers completed measures regarding sociodemographic background adolescent's cancer-specific stress, mother's general stress, mother-adolescent communication, and adolescent QOL. Survivors also reported on their own QOL. Two hierarchical multiple regressions examined predictors of: (a) mother's report of adolescent QOL and (b) survivor's self-report of QOL. **Results:** The final model predicting mother-reported adolescent QOL was significant, $F(5,74)=21.18$, $p<.001$, and explained 59% of the variance in QOL. Significant predictors included adolescent stress ($\beta=-0.37$, $p<.001$), mothers' stress ($\beta=-0.42$, $p<.001$), and communication ($\beta=0.19$, $p=.03$). The final model predicting survivor-reported QOL was also significant, $F(5,44)=5.16$, $p<.01$ and explained 24% of the variance in QOL. Significant predictors included adolescent stress ($\beta=-.37$, $p=.01$) and communication ($\beta=-.31$, $p=.04$). Sociodemographic factors were not a significant predictor of QOL in any model. **Conclusion:** Family stress and communication offer potential points of intervention to improve QOL of pediatric cancer survivors from mother and survivor perspectives. While additional research is needed, healthcare professionals should encourage stress management and strong mother-child communication to enhance survivors' long-term QOL. Such interventions may be helpful, irrespective of known sociodemographic factors that often affect health.

Introduction

Despite successful efforts to improve survival and reduce morbidity over the past several decades, pediatric cancer remains a significant stressor for families [1]. Although the diagnosis can occur in any family, the resulting burdens can depend, in part, on the family's sociodemographic background [2]. For example, income, parent education, and household size can determine a family's ability to cover the costs of treatment, travel to the hospital, and manage complex regimens at home [2]. These factors can also determine the capacity of caregivers to balance work and caregiving demands, resulting in risk for financial toxicity [3]. Furthermore, pre-existing sociodemographic and family stressors may be simultaneously exacerbated by cancer-related stress, affecting how well families manage the burdens of the disease. Thus, the family's success in navigating the pediatric cancer experience may have significant implications for the child's long-term quality of life (QOL).

QOL in childhood incorporates functioning in emotional, physical, social, and academic domains [4]. Children on treatment for cancer often experience significant impairment in QOL compared to children from

healthy populations [5]. Although attention to social determinants of health have grown, limited research has examined sociodemographic factors in the context of pediatric cancer and long-term QOL. However, similar work has been conducted on stress as the outcome in pediatric cancer populations. One study showed that at the bivariate level, sociodemographic factors (i.e., single parenthood, family income, education level, and race) were significantly associated with some but not all indicators of mothers' and children's stress and distress near diagnosis [2]. Another study found that children with advanced cancer from low-income families experienced a higher prevalence of pain and more distress compared with children from high-income families [6]. Children from low-income families also reported worse QOL [6].

Parents of cancer survivors can face a multitude of stressors including relapse, secondary effects of illness and treatment, continued costs, or supporting siblings. One study showed that mothers of children on treatment had higher levels of perceived stress and a less positive image of themselves as parents than mothers of healthy children [7]. Children also report significant stress during treatment, such as disruptions in daily/role functioning, physical effects of treatment, uncertainty about the disease, and fears about death [8,9]. Specifically, children find impairment in daily/role functioning (e.g., not being able to do the things they used to do) more stressful than uncertainty about their disease or chances for survival [8]. Thus, when examining predictors of quality of life in pediatric cancer survivors, it is important to consider both parental and child experiences of cancer-related stress, in addition to sociodemographic background and pre-existing family stress.

Cancer also creates demands relative to supportive communication between parents and their child. Communication is an important aspect of the parent-child relationship that demonstrates the level of trust, intimacy, and conflict between the two [10]. Over the past 30 years, there has been a shift from avoidance of communication about pediatric cancer to an emphasis on parents and children having straightforward discussions about diagnosis and prognosis [11]. For example, relative to healthy controls, mothers' openness and problems in communication may be similar over the first year after diagnosis or relapse regardless of whether children had advanced or non-advanced cancer [12]. One study found that childhood cancer survivors who reported better quality relationships with their mothers and fathers consistently reported better QOL [13], while research in other pediatric populations have linked parent-child communication with both child adjustment and adherence [14,15,16].

Despite the literature demonstrating the respective impact of sociodemographic factors, parent and child stress, and parent-child communication on quality of life, no studies to date have prospectively examined the combined effects of these factors on the long-term quality of life of pediatric cancer survivors. The present research examines associations between early sociodemographic (e.g., mother age, mother education, family income, number of children, number of parents, and race), family stress (i.e., mother's general stress, adolescent's cancer-specific stress), mother-adolescent communication on the quality of life of survivors at five years' post-diagnosis. We hypothesized that higher levels of cumulative sociodemographic risk, mother's general stress, adolescent's cancer-specific stress, and lower quality of mother-adolescent communication near diagnosis would predict lower quality of life for survivors five years later.

Methods

Procedure

Participants were from a pilot study and a multisite study in which both assessed, coping, communication, and adjustment in families of children with cancer from diagnosis to five years post-diagnosis. Following approval from the Institutional Review Board, eligible participants were selected from cancer registries and recruited by research staff at two large pediatric hospitals in the United States (one in the Midwest, one in the Southeast). Participants were recruited following either an initial cancer diagnosis or relapse. Parents were provided with information about the study and gave their written consent for participation. Children also gave their written consent or assent (for ages 10-17). Paper and pencil surveys were then completed at their convenience. After finishing the surveys at initial diagnosis (T1), families were contacted for follow-up assessments at one (T2), three (T3), and five years (T4) post diagnosis or relapse [17]. The families were

compensated for their time at each assessment.

Participants

Eligible children (a) had a primary cancer diagnosis or new recurrence of cancer (b) were aged between 5-17 at time of recruitment (c) were fluent in English (including parents). Children and parents were deemed ineligible if they had a pre-existing neurodevelopmental disorder or disability that precluded completion of measures. At the time of enrollment, 336 families participated.

At five years post-diagnosis, 18% ($n = 59$) of children from enrollment had passed away [17]. Of 277 approached families, 45% ($n = 124$) participated. For the current manuscript, the final sample included only mothers ($N=80$) and children ($N=50$) who completed mother proxy-reported QOL and adolescent self-reported QOL at 5-year follow up.

Measures

Demographic Questionnaire. Family demographic characteristics were provided by parents using a questionnaire that assessed factors such as marital status, education, occupation, religious beliefs, income, and number and age of children at enrollment (T1). A cumulative sociodemographic score was created from the information collected in this measure.

Perceived Stress Scale (PSS). This widely used 10-item instrument assesses subjective experiences of psychological stress [2,17]. Mothers rated each item on a 4-point scale of how often each item was true for them within the past month [2]. Internal consistency, test-retest ability, and concurrent and predictive validity have all been established [18]. Internal consistency in the current sample was low, $\alpha = .55$.

Responses to Stress Questionnaire- Pediatric Cancer Version (RSQ-PC). The RSQ-PC is a 57-item measure that includes a list of 11 cancer-related stressors (e.g., missing school, frequent hospital or clinic visits, changes in personal appearance) using a four-point scale ranking items from “Not at all” to “Very” [19]. Mothers provided proxy-report on their children. Prorated mean scores were calculated for overall cancer-related stress. The RSQ-PC has been used extensively with acceptable reliability and validity [20,21,22]. Internal consistency in this sample was high, $\alpha = .92$.

Parent-Adolescent Communication Scale (PACS). This questionnaire includes 20-items rated 1-5 regarding the quality of general communication between parents and their adolescents [23]. The measure includes 2 subscales: (a) Open Family Communication and b) Problems in Family Communication. A total communication score is calculated by coding the open family communication subscale so that higher scores indicate more openness, and reverse coding the problems in family communication subscale so that higher scores indicate fewer problems in parent-adolescent communication. The scales demonstrate internal consistency and adequate 4-week test-retest reliability [23]. Mother’s provided self-report of communication with their adolescent. Internal consistency in the current sample was acceptable, $\alpha = .70$.

Pediatric Quality of Life Inventory Version 4.0 (PedsQL). The PedsQL 4.0 is an established measure of health-related quality of life (HRQOL) and includes 23-items across four subscales: physical, emotional, social, and school functioning [24]. Items are reverse coded and linearly transformed to a scale of 0-100, with higher scores indicating better HRQOL. Parents provided proxy-report of their child’s QOL, and survivors provided self-report. One version was used for children ages 8-12 years old, and another was used for children ages 13-18 years old. The PedsQL has been used extensively to evaluate the HRQOL of children with chronic health problems [24]. The reliability and validity of this instrument have been established in previous work for youth aged 5-18 [25]. Internal consistencies in the current sample were $\alpha = 0.89$ for mother proxy-report, and $\alpha = 0.88$ for child self-report, which are deemed good.

For the current manuscript, each measure was administered at enrollment, except the Peds-QL, which was administered at 5-year follow up.

Analysis Plan

Analyses were conducted using SPSS (v.26). Descriptive statistics were conducted to examine the frequencies, mean and standard deviation of sociodemographic factors, cancer-specific stress, general stress, parent-adolescent communication, and HRQOL. Similar to previous work, the impact of sociodemographic factors was examined by creating a cumulative sociodemographic score [2]. Each sociodemographic variable of interest was dichotomized so that participants scored a 0 or 1 to indicate lesser or greater risk [2]. The scoring is as follows: multi-adult (0) vs. single-adult (1) household status, income > \$50,000 (0) vs. income [?] \$50,000 (1), mother education > 12th grade (0) vs. mother education [?] 12th grade (1), White race (0) vs. non-White race (1), and 0-2 children living in the household (0) vs. 3 or more children living in the household (1). Bivariate correlations were conducted to examine associations between the sociodemographic score, mother's general stress, adolescent's cancer-related stress, mother-adolescent communication, and survivor HRQOL (mother proxy-report and child self-report) at 5 years' post-diagnosis (Table 1).

Two hierarchical regressions were used to examine predictors of: (a) mother's proxy-report of survivor QOL and (b) survivor's self-report of HRQOL. In Step 1, only mother's age and the sociodemographic score were included. Step 2 included adolescent's cancer specific stress and mother's general stress. Lastly, Step 3 added mother-adolescent communication.

Results

Sample Characteristics

Table 1 summarizes descriptive information for mother and child factors, as well as the predictor and outcome variables. Most mothers were on average 37.83 years old ($SD = 7.59$), White ($n = 69$; 86.3%), partnered ($n = 59$; 73.8%), and had completed at least a high school diploma ($n = 65$; 81.3%). The number of families making above or below \$50,000 per year was similar. Survivors were on average 15.43 years old ($SD = 3.87$) at T4 and mostly male ($n = 41$; 51.2%). A large portion of survivors were diagnosed with either Leukemia ($n = 32$; 40%) or other solid tumors ($n = 28$; 35%) and on average had been off treatment for 3.61 years ($SD = 1.23$).

Descriptive Statistics and Correlations among Variables of Interest

Mean QOL scores based on mother proxy-report and survivor report were in the normal range and above clinical cutoff scores (65.4 and 69.7, respectively) [24]. Initial examination of associations between demographic/medical factors (i.e., sociodemographic score, survivor age, survivor sex, mother age, time since treatment) and QOL revealed only a significant association between the sociodemographic score and mother-reported survivor QOL, $r(80) = -.42, p < .001$. However, bivariate correlations revealed significant associations between mother-reported survivor QOL and mother-reported survivor's cancer specific stress, mother's general stress, and parent-adolescent communication (see Table 2). Bivariate correlations also revealed a significant association between survivor-reported QOL and mother report of survivor's cancer-specific stress (Table 2).

Longitudinal Predictors of Mother-reported Survivor Quality of Life

A hierarchical regression model examined baseline predictors of mother-report of survivor quality of life at 5-year follow-up. The first step examined mother's age and the sociodemographic score. This model was significant, $F(2,77) = 8.38, p < .001$, and explained 18% of the variance in QOL. The sociodemographic score was the sole significant predictor ($\beta = -0.39, p < .001$). The second step added mother-report of survivor's cancer-specific stress and mother's general stress, which contributed an additional 38% of explained variance in QOL, $\Delta\Phi(2,75) = 32.41, p < .001$. Both mother-report of survivor's cancer-specific stress ($\beta = -0.39, p < .001$) and mother's general stress ($\beta = -0.46, p < .001$) were significant predictors of QOL, but the sociodemographic score was no longer a significant predictor. Finally, mother-adolescent communication was added in the third step of the model and contributed an additional 3% of variance in QOL, $\Delta\Phi(1,74) = 5.26, p = .03$. This final model was significant, $F(5,74) = 21.18, p < .001$, and explained 59% of the total variance. With the addition of mother-adolescent communication, survivor's stress ($\beta = -0.37, p < .001$), mother stress ($\beta = -0.42, p < .001$), and communication ($\beta = 0.19, p = .03$) were all significant predictors of

quality of life (Table 3).

Longitudinal Predictors of Survivor-reported Quality of Life

A second hierarchical regression model examined predictors of survivor-reported QOL using the same variables in the first model. In the first step, we examined mother’s age and the sociodemographic score. This model was not significant, $F(2,47) = 0.70, p = .504$, as it only explained 3% of the variance in QOL. In the second step, mother-report of survivor’s cancer-specific stress and mother’s general stress were added. This model was significant, $\Delta\Phi(2,45) = 3.50, p = .039$, and added 13% of explained variance. Only mother-report of survivor’s cancer-specific stress ($\beta = -0.56, p = .022$) was a significant predictor. In the third and final step, mother-adolescent communication was added and contributed 8% of explained variance to the model, $\Delta\Phi(1,44) = 4.37, p = .042$. With the addition of mother-adolescent communication, survivor’s cancer-related stress ($\beta = -0.37, p = .011$) and communication ($\beta = -0.31, p = .042$) were significant predictors of survivor-reported quality of life. This final model was significant as well, $F(5,44) = 2.71, p = .032$ and explained 24% of the variance in the long-term QOL of survivors (Table 4).

Discussion

Limited research has examined early sociodemographic and family factors near diagnosis that predict long-term QOL among childhood cancer survivors. The goal of this study was to examine the relative impact of sociodemographic factors using a cumulative risk score, mother’s stress, survivor’s cancer-specific stress, and mother-adolescent communication on later QOL of survivors. We expected that a higher cumulative sociodemographic score (i.e., higher risk) would lead to lower levels of QOL in survivors. Survivor QOL was, on average, in the normative range at 5-year follow-up. Contrary to our hypothesis, the sociodemographic score was not a significant predictor of QOL when other factors like cancer-related stress and communication, were considered. While these results did not align with our expectations for the sociodemographic score, they demonstrate the lasting importance of more proximal family factors in relation to later QOL in long-term survivors.

In both the mother-reported model and the survivor-reported model, earlier exposure to stress consistently predicted long-term QOL, whether it was survivor’s cancer-specific stress or mother’s general stress. The mother-reported model explained almost 60% of the variance in survivor QOL, with survivor’s cancer-specific stress and mother’s general stress contributing 38% of explained variance in the model. These results support our hypothesis about stress and are consistent with literature finding that stress and negative emotions in response to a chronic illness, such as cancer, can affect QOL [26]. For survivor-report of QOL, the addition of survivor’s cancer-specific stress and mother’s general stress contributed 13% of explained variance in QOL, with the overall model explaining 24% of the variance in long-term QOL. However, only cancer-specific stress was a significant predictor. Thus, survivors’ QOL may be affected more by their own stress specifically related to their diagnosis, than their mother’s general stress. To our knowledge, this is the first study that has examined the longitudinal impact of general and cancer-related stress on survivor-reported QOL in a pediatric cancer sample.

In both models, higher quality of mother-adolescent communication was a significant predictor of better QOL, particularly with respect to child-report of QOL. These results support our hypothesis that communication has a significant impact on survivors’ QOL. Previous research in pediatric populations has found that a high quality of family communication enhanced adolescents’ life satisfaction [27]. Other studies have also identified family communication as a correlate of important developmental, psychosocial and health outcomes [14,28,29].

While research has largely focused on medical predictors of QOL in pediatric cancer, few studies have examined the longitudinal impact of family factors near diagnosis, such as stress and communication, on later QOL. The present research shows that these factors should not be overlooked. Each of these factors were both associated with QOL and were significant predictors over time. Although cumulative sociodemographic factors did not predict long-term QOL in our final models, they were significantly correlated with mother-reported QOL. They were also associated with early outcomes, which is similar to previous findings [2], and

were significantly correlated with mother’s general stress, adolescent’s cancer-specific stress, and mother-adolescent communication near diagnosis. Therefore, future research should continue to examine the role of sociodemographic factors and key outcomes over time.

Our study was limited by several factors. First, our sample was primarily White and non-Hispanic. Similar research should be conducted with a more diverse sample to examine if associations may vary as a function of race or ethnicity in regard to sociodemographic factors and QOL. We also examined only survivor-report and mother-report of family factors. Future research should solicit perspectives from fathers in addition to mothers and survivors to examine data from both parents. Importantly, the mother-proxy model may have been affected by common method variance, and multiple informants are necessary to test more robust models. Lastly our sample was comprised of mothers who were largely partnered, had few children per household, and had an education of at least a high school diploma, resulting in a relatively low-risk sample. This could have explained why the cumulative sociodemographic score was no longer a factor when stress and communication were examined concurrently. Future research should continue to identify other social and family factors early in the cancer trajectory that may influence the long-term QOL of pediatric cancer survivors.

Our study also had several key strengths. First, the sample was recruited soon after a child was diagnosed with cancer or had relapsed and was followed longitudinally over five years. This allowed us to identify early predictors of later outcomes in long-term survivorship. Second, the sample was inclusive in terms of different diagnoses, allowing us to examine QOL in children affected by pediatric cancer more broadly, rather than focusing on one type of diagnosis. This research is unique in its family-centered approach assessing both general stress and cancer-specific stress, as well as multiple viewpoints (parent self-report, parent proxy-report of survivor, survivor self-report). Limited research has examined the contributions of sociodemographic and family factors that predict QOL in youth affected by pediatric cancer.

This information can help inform family-centered care to improve long-term QOL in pediatric cancer survivors. Despite the effects of cumulative sociodemographic risk, family stress and communication may offer potential points of intervention to improve QOL of pediatric cancer survivors over time. Clinicians should assess family and cancer-related stress, as well as facilitate open and honest communication early in treatment to reduce risks. Previous psychosocial interventions have shown promise in the areas of physical, psychological, and social-relational aspects of quality of life [30, 31]. While additional research is needed, healthcare professionals should encourage stress management and strong mother-child communication to enhance survivors’ long-term QOL. Such interventions may be helpful, irrespective of known sociodemographic risk factors that often affect health.

Conflict of Interest Statement

The authors declare that there are no conflicts of interest.

Acknowledgements

We would like to thank the families who participated and our funding source, the National Cancer Institute and intramural funding from the Abigail Wexner Research Institute at Nationwide Children’s Hospital.

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TABLE 1. Sample Characteristics of Participants

	M (SD)	N (%)
Mother Factors		
Age	37.83 (7.59)	-
Income (< \$50,000)	-	39 (48.8 %)
Single	-	21 (26.3 %)
Education ($\leq 12^{\text{th}}$)	-	15 (18.8 %)
Children (≥ 3)	-	30 (37.5 %)
Race (Non-White)	-	11 (13.8 %)
Child Factors		
Gender (Male)	-	41 (51.2%)
Age at diagnosis	9.68 (3.75)	-
Age at 5-year follow up	15.43 (3.87)	-
Time Since Tx (Years)	3.61 (1.23)	-
Leukemia		32 (40%)
Lymphoma		14 (17.5%)
Brain Tumor		5 (6.3%)
Other Solid Tumor		28 (35%)
Stress		
Adolescent's Cancer-Specific Stress	19.20 (7.50)	-
Mother's General Stress	15.93 (7.09)	-
Mother-Adolescent Communication	80.18 (8.55)	-
Quality of Life		
Mother-reported QOL	79.84 (14.61)	-
Adolescent-reported QOL	83.14 (13.30)	-

TABLE 2. Pearson Correlations Among Variables of Interest

Measure	1	2	3	4	5	6	7	8	9	10
1. Cum. Risk	-									
2. Child Age	-.177	-								
3. Child Sex	.091	.033	-							
4. Mother's Age	-.379**	.642**	.046	-						
5. Time Since Tx	-.014	.199	.338*	.172	-					
6. RSQ-PC	.334**	-.092	-.045	-.142	-.034	-				
7. PSS	.337**	-.146	.005	-.245*	-.126	.404**	-			
8. PACS	-.319**	-.044	-.014	.172	.021	-.290**	-.309**	-		
9. M PQOL	-.418**	.048	.000	.215	.236	-.508**	-.615**	.432**	-	
10. C PQOL	-.149	.132	-.214	.124	.083	-.433**	-.215	-.134	.478**	-

TABLE 3. Longitudinal Predictors of Mother-reported Survivor Quality of Life

Mother-reported Survivor QOL (N=80)	Variance Captured
Step 1 <ul style="list-style-type: none"> • Mother's Age • Cumulative Sociodemographic Score 	$R^2 = 18\%$
Step 2 <ul style="list-style-type: none"> • Mother's General Stress* • Survivor's Cancer Specific Stress* 	$R^2 = 56\%$
Step 3 <ul style="list-style-type: none"> • Mother-Adolescent Communication* 	$R^2 = 59\%$

*Significant Predictor in Final Model

TABLE 4. Longitudinal Predictors of Survivor-reported Quality of Life

Survivor-reported QOL (N=50)	Variance Captured
Step 1 <ul style="list-style-type: none"> • Mother's Age • Cumulative Sociodemographic Score 	$R^2 = 3\%$
Step 2 <ul style="list-style-type: none"> • Mother's General Stress • Survivor's Cancer Specific Stress* 	$R^2 = 16\%$
Step 3 <ul style="list-style-type: none"> • Mother-Adolescent Communication* 	$R^2 = 24\%$

*Significant Predictor in Final Model