


Associations of Age, Gender, and Family Income with Quality of Life in Children With Advanced Cancer

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Abstract

Background: Children with cancer often experience decreased quality of life (QOL) throughout the illness trajectory. The purpose of this study was to explore the associations of demographic characteristics with QOL in children with advanced cancer. **Methods:** This secondary analysis was part of a larger randomized clinical trial that evaluated the efficacy of a legacy intervention for children (7–17 years) with relapsed/refractory cancer and their primary parent caregivers. Assessments included child self-reports on the Pediatric Quality of Life Inventory (PedsQL) Cancer Module. Researchers used descriptive and linear regression statistical methods. **Results:** Children ($n = 128$) averaged 10.9 years ($SD = 3.0$). The majority were female ($n = 68$, 53%), white ($n = 107$, 84%), had a hematologic malignancy ($n = 67$, 52%), with family incomes of \$50,000 or less ($n = 81$, 63.3%). Statistically significant positive associations of both age and income level with PedsQL scores were observed ($p < .05$) but not gender ($p > .05$). The strongest correlations for age were with the procedural anxiety ($beta = 0.42$), treatment anxiety ($beta = 0.26$), and total ($beta = 0.28$) scores (all $p < .01$). In general, there was a positive correlation between family income levels and PedsQL scores ($p < .05$). The strongest correlations for income were with nausea ($R = 0.49$), appearance ($R = 0.44$), pain, and treatment anxiety (both $R = 0.42$) (all $p < .01$). Associations adjusted for age remained essentially the same (all $p < .01$). **Discussion:** Children with advanced cancer with lower family income and younger age are at high risk for poorer QOL. Oncology nurses should seek to identify families who may benefit from additional resources to promote QOL.

Keywords

quality of life, pediatric cancer, advanced cancer, family income

Introduction

Children with cancer experience substantial suffering and decreased quality of life (QOL) throughout their illness trajectory (Dupuis et al., 2016; Eiser et al., 2017; McCullough et al., 2018; Rae et al., 2018; Rosenberg et al., 2016; Smith et al., 2013; Wolfe et al., 2015). Patient reported outcome measures (PROMs), including QOL assessment, offer clinicians insight into the patient's experience and symptoms and potentially improve communication between the patient and provider (Avoine-Blondin et al., 2018; Howell et al., 2015). The child self-report of QOL has been found to be reliable and valid and give children older than 5 years a voice through the use of age-appropriate measures (Varni et al., 2005, 2007).

The QOL of children with advanced cancer has not been extensively evaluated. To better understand the current knowledge on pediatric QOL in advanced cancer, a PubMed query was conducted. The terms advanced/relapsed/refractory cancer, QOL, and pediatric/child in the title or abstract yielded 38 results, of which 10

evaluated QOL in children with advanced cancer. Most of the publications describe the outcomes of the PediQUEST study (Bilodeau et al., 2019; Howite et al., 2018; Rosenberg et al., 2016; Ullrich et al., 2018; Wolfe et al., 2014, 2015). This was a multisite, prospective, longitudinal study at three urban, academic medical centers evaluating symptom distress and QOL in children with advanced cancer who were >2 years of age. The central findings of the PediQUEST study were that cancer symptoms, such as pain, sadness, fatigue, vomiting, and anorexia were associated with distress and lower QOL in children

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Table 1. Descriptive Summary of Sample Demographic and Clinical Characteristics (N = 128).

Characteristic	Mean (SD) N (%)
Age	10.9 (3.0)
Child sex	
Male	60 (46.9%)
Female	68 (53.1%)
Race (N = 126)	
White	107 (84.9%)
Black or African American	4 (3.2%)
Asian	2 (1.6%)
American Indian or Alaska Native	2 (1.6%)
Other	11 (8.7%)
Ethnicity (N = 126)	
Hispanic or Latino	15 (11.9%)
Not Hispanic or Latino	111 (88.1%)
Primary language	
English	124 (96.9%)
Spanish	4 (3.1%)
Location of permanent home	
Northeast	17 (13.3%)
Southeast	29 (22.7%)
Midwest	66 (51.6%)
Southwest	11 (8.6%)
West	5 (3.9%)
Current family income per year	
Under \$25,000	50 (39.1%)
\$25,001–\$50,000	31 (24.2%)
\$50,001–\$75,000	16 (12.5%)
\$75,001–\$100,000	15 (11.7%)
\$100,001 or more	16 (12.5%)
Malignancy type	
Hematologic	67 (52.3%)
Solid tumor	34 (26.6%)
CNS tumor	27 (21.1%)
History of:	
Cancer relapse or recurrence	88 (68.8%)
Secondary cancer (N = 127)	3 (2.4%)
Surgery to remove a tumor	53 (41.4%)
Chemotherapy treatments	121 (94.5%)
Radiation therapy	85 (66.4%)
Bone marrow transplant	22 (17.3%)
Phase I clinical research involvement	
Yes	22 (17.2%)
No	78 (60.9%)
Unsure	28 (21.9%)
Been told cancer is terminal	13 (10.2%)
Presence of active DNR order	2 (1.6%)
Currently enrolled in hospice	
Yes	2 (1.6%)
No	125 (97.7%)
Unknown	1 (0.8%)

(continued)

Table 1. Continued.

Characteristic	Mean (SD)
Currently enrolled in palliative care	
Yes	7 (5.5%)
No	115 (89.8%)
Unknown	6 (4.7%)
	Median (IQR)
Years since diagnosis (N = 127)	3.9 (1.8, 6.0)

Note. DNR: Do not resuscitate.

with advanced cancer (Rosenberg et al., 2016; Ullrich et al., 2018; Wolfe et al., 2014, 2015).

Few studies on pediatric cancer patients have explored the associations between QOL and demographic characteristics such as age, sex, and income. Two studies found that children under 5 years of age with acute lymphocytic leukemia (ALL) experienced greater treatment and procedural anxiety, which are dimensions of QOL assessment (Dupuis et al., 2016; Sitaresmi et al., 2008). However, this association between age and QOL was not found in the PediQUEST study (Rosenberg et al., 2016). Associations between gender and QOL have not been identified in children with cancer (Dupuis et al., 2016; Rosenberg et al., 2016; Sitaresmi et al., 2008).

Where the impact of socioeconomic status on adult cancer patients has been well described (Abel et al., 2016; Bilodeau et al., 2018; Bona et al., 2015; Macpherson et al., 2020; Santacroce & Kneipp, 2019), the association of a family's current financial situation on QOL in children with cancer has not been extensively explored. As part of the PediQUEST study, researchers explored associations of family income with QOL and symptoms in children with advanced cancer. They found that children whose families were in the low-income group (<\$50,000) had poorer total QOL than those in the high-income group (Ilowite et al., 2018). Common cancer symptoms such as fatigue, pain, and nausea were more prevalent in the lower financial brackets; however, only pain demonstrated a statistically significant difference ($p = .02$). This direct association with income and QOL was not replicated with those with ALL (Dupuis et al., 2016; Sitaresmi et al., 2008).

To improve QOL in pediatric oncology patients, there is a need to understand the demographic characteristics associated with poorer QOL for all cancer diagnoses so that interventions can be targeted to those who are most likely to benefit. The purpose of this study was to explore the associations of child demographic characteristics (age, gender, family income) with QOL in children with advanced cancer.

Methods

This study was a secondary analysis of data from an Institutional Review Board (140622, Vanderbilt

University) approved randomized clinical trial (RCT) that evaluated the efficacy of a web-based legacy intervention for children with advanced cancer and their parents (Akard et al., 2020). Legacy making has been defined as actions or behaviors aimed at being remembered (Akard et al., 2015, 2018, 2020). Complete details of the RCT are reported elsewhere (Akard et al., 2020). In brief, eligible children and their primary parent caregivers were recruited via Facebook advertisements (Akard et al., 2020). Children were aged 7–17 years without cognitive impairment, of any gender, with relapsed or refractory cancer (based on parent self-report) and living in the United States. Participants spoke and understood English and had internet access. Children and their primary parent caregivers provided verbal consent and assent. Families received up to \$275 as a thank you for participating in the study. The IRB waived the requirement for written consent. Child–parent dyads were randomized 1:1 to the intervention or usual care group. Parents reported child demographic information via an electronic survey.

Investigators collected and managed data using Research Electronic Data Capture (REDCap), a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources (Harris et al., 2019, 2009). Child and parent participants completed electronic measures for psychosocial outcomes (QOL, coping, child–parent communication) via REDCap at baseline/pre- (T1) and post-intervention (T2). This secondary analysis included child demographic and clinical characteristics and child QOL outcomes collected at the baseline time of assessment in the primary study. Participants were excluded from this study if QOL or family income data were missing. Since demographic characteristics were only collected at baseline, this study was limited to a cross-sectional evaluation at the time of enrollment.

Parents reported child demographic and clinical characteristics (noted in Table 1) on a demographic survey. Children self-reported their QOL on the 27-item Pediatric Quality of Life Inventory (PedsQL) Cancer Module 3.0. The instrument provides a total score and dimension scores for pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication (Varni et al., 2002). The young child (5–7), children (8–12), and teens (13–18) self-report scales were used (Varni et al., 2002). The original Likert responses (0–4) were recoded to a possible range of 0–100 and reversed so that higher scores represent better QOL. The

dimension and total scores were generated by calculating the mean of the recorded respective component items (Varni, 2017). Internal consistency of the child report total and dimension scores in this study ranged from 0.84 (perceived appearance) to 0.96 (both procedural and treatment anxiety).

Analysis

IBM SPSS Statistics (version 26) was used for analyzing the data. The sample demographic, clinical, and PedsQL score distributions were summarized and evaluated using descriptive statistics. Linear regression models were used to generate the unadjusted associations of child sex, child age, and family income level with each of the PedsQL scores, as well as the adjusted associations of income level controlling for child age. Age was measured on a continuous scale; therefore the standardized regression coefficient (*beta*) serves as an indicator of the strength of the association of that variable with each of the PedsQL scores. Income was assessed as ordinal categories, thus the association of income with each of the PedsQL scores was assessed by the multiple correlation (*R*) of the categories as a set of variables with each score. The adjusted multiple correlations of income with the PedsQL scores reflect those same correlations after controlling for the correlations of age with each of those respective scores (middle column). For statistical significance, an alpha of 0.05 was used ($p < .05$).

Results

The sample included 128 children for analysis. Demographic and clinical characteristics are summarized in Table 1. Child participants averaged 10.9 years (SD 3.0). There were slightly more female children than male, most were white with a hematologic malignancy and reported their primary language to be English. The majority of respondents lived in the Midwest region of the United States with a family income of \$50,000 or less ($n = 81$, 63.3%); 39.1% ($n = 31$) had an income of \$25,000 or less per year. The children were approximately 4 years (median) since initial diagnosis; a majority had suffered a relapse or recurrence but were not receiving palliative care or hospice services (see Table 1). Of the demographic characteristics of interest (age, race/ethnicity, primary language, and income), the sample was too small to include the relatively homogeneous characteristics of race/ethnicity and primary language (85% white, 88% non-Hispanic). Thus, only the characteristics of age, child sex, and family income were included in the analyses of associations with the PedsQL scores.

The children's PedsQL scores are summarized in Table 2. As shown, the median values tended to be

toward the middle of the possible range of scores with considerable variability in the scores. No statistically significant or meaningful associations of child gender with PedsQL scores were observed ($beta = 0.01-0.13$, $p > .10$). Associations of child age and family income level with each of the PedsQL scores are shown in Table 2. Age had statistically significant positive associations with the PedsQL total score and specifically with the procedural anxiety, treatment anxiety, communication, pain, and nausea dimension scores demonstrating that as age increased PedsQL scores tended to increase also. Family income level was statistically significantly positively associated with all of the PedsQL scores demonstrating that as income levels increased, PedsQL scores also tended to increase (all $p < .01$). The strongest correlations with the specific PedsQL dimensions were demonstrated for nausea, appearance, pain, and treatment anxiety (see Table 2).

Detailed summaries of the multivariate associations of age and income with the PedsQL scores are shown in Table 3. All of those multivariate associations with the scores were statistically significant (multiple $R > 0.30$, $p < .02$, Table 3). After controlling for the effects of family income, age remained statistically significantly

positively associated with the PedsQL total score ($beta = 0.19$, $p = .020$) however specifically, with only the two anxiety dimensions (procedural: $beta = 0.36$, $p < .001$; treatment: $beta = 0.18$, $p = .030$). After controlling for the effects of age, family income level remained statistically significantly positively associated with all of the PedsQL scores (adjusted $R > 0.27$, $p < .02$, Table 3). As is apparent from the patterns of the $beta$ coefficients for each of the increasing income levels (compared to $< \$25,000$), there was a generally increasing positive effect of income on the QL scores with each increase in family income level (see Table 3).

Discussion

This was the largest known study of its kind to examine associations of child demographic variables with QOL in children with advanced cancer. While other studies have limited recruitment to a new cancer diagnosis, a specific cancer type, and/or one health system (Bilodeau et al., 2018; Bona et al., 2015, 2016; Dupuis et al., 2016; Ilowite et al., 2018; Phipps et al., 2002; Rosenberg et al., 2016), this unique dataset represented children across the United States with any type of relapsed or refractory cancer. This distinguishes our study from the PediQuest study, which was limited to children receiving care at three coastal, urban medical centers (Rosenberg et al., 2016).

Results demonstrated a statistically significant impact of younger age on the adjusted total and anxiety (procedural and treatment) scale scores, similar to the few studies that have previously explored and published correlations between child age and QOL (Dupuis et al., 2016; Sitaresmi et al., 2008). The effect sizes in our study were smaller than those noted in the Dupuis et al. (2016) study. The difference in effect size between the studies may be attributed to the difference in the ages included in each sample (2–9.9 years (Dupuis et al., 2016) and 2–18 years (Sitaresmi et al., 2008) compared to 7–18 years in our study). Another potential explanation for the difference in effect size is the difference between the proxy parental report used for the younger age groups in Dupuis et al. (2016) and Sitaresmi et al. (2008) compared to our study that only used child self-report. Although previously reported correlations between the patient ($r = 0.89$) and parent ($r = 0.81$) report are high, some studies have found that parents may over-report children's symptoms (Lawitschka et al., 2014; Parsons et al., 2012; Waters et al., 2003).

Gender differences did not impact QOL, which is consistent with other studies that have explored QOL in children with ALL using the PedsQL instrument (Dupuis et al., 2016; Rosenberg et al., 2016; Sitaresmi et al., 2008). However, in a similar sample of 104 children

Table 2. Descriptive Summaries of the Pediatric Quality of Life Inventory (PedsQL) Scores and Associations of Age and Income Level With Those Scores ($N = 128$)^a.

PedsQL score	Median (IQR)	Child age r (p -value)	Family income level R (p -value)
Total	49.5 (24.4, 67.7)	0.28 (.002)	0.48 ($<.001$)
Pain ($N = 127$)	37.5 (12.5, 62.5)	0.20 (.024)	0.42 ($<.001$)
Nausea	45.0 (20.0, 70.0)	0.20 (.022)	0.49 ($<.001$)
Procedural anxiety	41.7 (0.0, 66.7)	0.42 ($<.001$)	0.36 (.002)
Treatment anxiety	50.0 (25.0, 83.3)	0.26 (.003)	0.42 ($<.001$)
Worry	41.7 (16.6, 66.7)	0.11 (.226)	0.32 (.009)
Cognitive problems	45.0 (25.0, 65.0)	0.17 (.051)	0.36 (.002)
Appearance	64.6 (25.0, 83.3)	0.17 (.059)	0.44 ($<.001$)
Communications	58.3 (25.0, 83.3)	0.24 (.007)	0.39 ($<.001$)

^aAge was measured on a continuous scale therefore the Pearson correlation coefficient was used to assess those correlations with the PedsQL scores. Income was measured as ordinal categories thus the association of income with each of the PedsQL scores was assessed by the multiple correlation (R) of the categories as a set of variables with each score.

Table 3. Multivariate Associations of Age and Income with Pediatric Quality of Life Inventory (PedsQL) Total and Domain Scores.

Characteristic	PedsQL score								
	Total	Pain	Nausea	Procedural anxiety	Treatment anxiety	Worry	Cognitive problems	Appearance	Communications
Model multiple R (p-value)	0.51 (<.001)	0.44 (<.001)	0.51 (<.001)	0.50 (<.001)	0.46 (<.001)	0.32 (.018)	0.38 (.002)	0.45 (<.001)	0.42 (<.001)
Age	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)
	0.19 (.020)	0.13 (.127)	0.13 (.107)	0.36 (<.001)	0.18 (.030)	0.04 (.661)	0.11 (.194)	0.07 (.388)	0.17 (.051)
Income adjusted R (p-value)	0.43 (<.001)	0.39 (<.001)	0.46 (<.001)	0.28 (.018)	0.38 (<.001)	0.30 (.016)	0.34 (.004)	0.42 (<.001)	0.35 (.002)
Income	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)	beta (p-value)
<\$25,000	0.21 (.016)	0.14 (.133)	0.24 (.007)	0.14 (.120)	0.16 (.088)	0.21 (.031)	0.21 (.028)	0.26 (.006)	0.06 (.549)
\$25-50,000	0.28 (.002)	0.23 (.014)	0.15 (.078)	0.18 (.037)	0.26 (.005)	0.21 (.030)	0.14 (.135)	0.31 (.001)	0.30 (.001)
\$50-75,000	0.39 (<.001)	0.36 (<.001)	0.41 (<.001)	0.27 (.002)	0.34 (<.001)	0.27 (.004)	0.30 (.001)	0.35 (<.001)	0.23 (.011)
>\$100,000	0.30 (.001)	0.28 (.002)	0.38 (<.001)	0.07 (.421)	0.25 (.005)	0.20 (.036)	0.26 (.005)	0.29 (.001)	0.23 (.010)

^aReferent group for family income level.

with advanced cancer aged 2–17 years, female gender (2.28 (95% CI 0.14–4.42), $p = .04$) was associated with higher symptom burden using the Memorial Symptom Assessment Scale (Wolfe et al., 2015). Other correlates of symptom burden were diagnosis of a brain tumor, recent disease progression, and recent moderate-to-high-intensity chemotherapy (Wolfe et al., 2015). Additional research is needed to determine whether gender has an agnostic effect on QOL and the relationship between symptom burden and gender.

The findings of this study suggested that lower family income was correlated with poorer child QOL. The proportion of low-income participants (<\$25,000 annually) in this study was 39.1%, which is greater than the reported national average of 19.2% (Semega et al., 2020). The impact of financial hardship and toxicity has been well described, and lower income has been associated with poorer outcomes, including increased incidence of graft versus host disease (GVHD) following allogeneic transplant (Bilodeau et al., 2018; Bona et al., 2015). Parents of children with cancer report living paycheck to paycheck and decreasing contributions to retirement, insurance, and college funds to pay for healthcare expenses (Bilodeau et al., 2018; Bona et al., 2015). This is one of the largest known studies to note a statistically significant correlation between income and total and scale PedsQL, supporting the findings of Ilowite et al. (2018).

This secondary analysis was limited by the cross-sectional design. It is unknown if families suffered financial toxicity due to childhood cancer or were already in low socioeconomic brackets pre-cancer, which may have influenced child QOL. Future studies should assess for change in socioeconomic status over time and evaluate the impact of this change. Low-income participants are over-represented in this sample compared to the national average, which could have been due in part to selection bias due to financial incentives. There is a sampling threat created by convenience sampling of enrollment after interaction with a Facebook advertisement. Future research should explore factors that motivate enrollment for clinical studies through social media platforms. Finally, this study was limited to child and parent self-reports. Therefore, the means of assessing family income was subjective rather than an objective source such as tax returns.

This study emphasizes the importance of assessing financial hardship and appreciating the impact age and financial status has on the QOL in children with advanced cancers. Oncology nurses should screen pediatric patients to identify families who may benefit from additional resources and supportive care to promote QOL. Future research could tailor QOL interventions to low-income families and young children as these families may be more likely to benefit.

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