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Social-ecological predictors of school functioning in Hispanic Children of cancer with central nervous system-directed therapies

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1 BACKGROUND

The 5-year survival rate for patients with pediatric cancer has increased to over 80%.¹ Consequently, there are more than 400,000 childhood cancer survivors (CCSs) in the United States.² Two-thirds will experience at least one long-term consequence of their cancer and its treatment.³ The intensive treatment schedules, which require absence from school, can further disrupt the psychosocial development of the child. Thus, a combination of cancer-specific effects, treatment-related impairments, missed school days, and psychosocial effects (such as school avoidance) can act together to negatively impact long-term school and educational functioning.⁴ These children may struggle at school and experience poor functional outcomes into adulthood, including lower educational attainment, increased use of special education services, and higher unemployment.⁵⁻⁷

Established risk factors for long-term functional impairments include a brain tumor diagnosis, central nervous system (CNS)-directed chemotherapy and/or cranial radiation, younger age at diagnosis, and longer time since treatment.⁸⁻¹¹ Some research, but not all, from our group and others suggests that CCSs from ethnic minority and/or lower socioeconomic backgrounds are at further risk for worse cognitive and health-related quality of life (HRQOL) outcomes following cancer.¹²⁻¹⁷ The Hispanic population is now the largest ethnic or racial minority in the United States and it is estimated that Hispanic people will account for close to one-third (29%) of the population by 2060.¹⁸ While social-ecological factors appear especially relevant for CCSs from socioeconomically disadvantaged groups, they have not been studied, despite the potential to inform tailored intervention approaches to improve outcomes. To help address this gap in the literature, we examined these factors in a sample of Hispanic CCSs treated with CNS-directed therapies

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

from predominantly Spanish-speaking homes, as this is a group that is overrepresented in the low-socioeconomic status strata.

Using a social-ecological systems perspective,^{19,20} we considered the dynamic interplay among multiple factors that could impact the child's developmental progression, such as the child's motivation, family environment, and availability and quality of school and neighborhood resources. For this study, we evaluated three candidate factors. First, we chose to examine parent education level as one of the social-ecological factors. Prior research in the general population, as well as anecdotal observations in pediatric oncology, suggest that children's academic and school progress is influenced by family resources.^{19,20} These resources are often represented by socioeconomic indicators such as parent education and household income. Family resources are also associated with parents' ability to advocate for appropriate services at school or to provide academic resources outside of school.²¹⁻²³

Second, we chose to examine the child's motivation for educational success. In the educational literature, the child's motivation to learn and interest in doing well at school are important determinants of educational success. Increased child motivation has been positively associated with school success among healthy populations,^{24,25} and children with higher intrinsic motivation tend to show more self-regulation and persistence when faced with learning challenges.^{26,27}

We chose parenting knowledge as a third social-ecological factor to examine in this study. Among children with neurocognitive and learning impairments, high motivation alone is unlikely to be sufficient to help the child progress in school. In keeping with social-ecological theory, parenting behaviors that support the child's progress are instrumental daily processes that impact the skills and traits their children develop. In particular, parents' knowledge about how to help their child with learning and school issues, including identifying educational and school resources, tools, and learning strategies, may influence school functioning. Therefore, the objective of this study was to examine whether these a priori selected social-ecological factors contribute toward suboptimal school HRQOL in Hispanic children treated with CNS-directed cancer therapies, after accounting for effects associated with established cancer-related risk factors. We hypothesized that parenting knowledge would predict school HRQOL in Hispanic children treated with CNS-directed therapies, even after accounting for the variance associated with (a) the child's age, (b) well-established cancer-related risk factors, (c) family socioeconomic status, and (d) the child's school motivation.

1 METHODS

1.1 Participants

The sample consisted of 73 Hispanic caregivers of children treated with CNS-directed cancer therapy for a brain tumor or leukemia. Recruitment was described previously.¹⁷ To summarize, we partnered with a community organization, PADRES Contra El Cáncer (Parents Against Cancer), to access eligible participants. PADRES is a nonprofit organization providing educational and supportive services for Hispanic children with cancer and their families at various pediatric cancer centers in the greater Los Angeles area, and

they maintain a database of patient contact information. Approximately 60% of the families served by PADRES only speak Spanish. Eligible families in the PADRES database served as the pool from which participants were recruited. Three families were initially identified through the Childhood Cancer Survivorship Program at City of Hope and were also in the PADRES database.

Individuals were eligible if they were a parent or primary caregiver of a child between ages 6 and 18 years. Although some children had multiple parents living in the home, only one parent was a study participant. Eligible families had a child who completed treatment for acute leukemia (ALL or AML) or brain tumor, was in remission, and was enrolled in school. The caregiver had to live with the child, self-identify as Hispanic/Latino, and could be either English or Spanish speaking.

All 103 eligible parents were contacted for study participation and 70.9% ($n = 73$) agreed to participate and completed the study measures. Nonparticipants did not respond to phone calls and reasons for study decline are not known. Study questionnaires were mailed to participants for completion in their preferred language. The study materials were read over the phone as needed (24%). The study was approved by the City of Hope Institutional Review Board. All participants provided informed consent before study participation.

1.2 Measures

1.2.1 Demographic and health information—Participants completed a questionnaire providing family sociodemographic data and health information for their child, including cancer diagnosis and treatment-related details. Prior to data collection, all questionnaires (except for the Pediatric Quality of Life Inventory [PedsQL]) and procedures were adapted with input from an advisory panel consisting of Latino parents of CCSs and bilingual health professionals (health educator, advanced nurse, psychologist, and pediatric oncologist) from the Latino community. The panel gave feedback and assisted in adapting materials to better reflect the experiences of low acculturated Latino participants and those with low levels of education and literacy. The adapted questionnaires were then translated into Spanish using standard translation and back translation methodology and pilot tested with six Latino parents of CCSs prior to data collection.

1.2.2 HRQOL school functioning scale—The child's school HRQOL was assessed by the School Functioning Scale of the PedsQL 4.0 Generic Core Scales-Parent Report, a widely used measure of HRQOL that has been validated for use in caregivers of patients with childhood cancer.²⁸ The PedsQL school functioning scale consists of five items asking the caregiver how much of a problem their child has with school-related functioning such as paying attention in class, forgetting things, keeping up with schoolwork, and missing school. Caregivers rate their child's HRQOL on a scale of 0 (never) to 4 (almost always). Items are reverse-scored and transformed to a 0-100 scale, so that higher scores indicate better HRQOL. This measure has been validated among Hispanic parents in both English and Spanish and has good reliability ($\alpha = .74$).^{28,29} The PedsQL school functioning scale is associated with child performance scores on objective academic achievement testing³⁰ and previously has been used as a measure of school functioning in research.³¹⁻³³

1.2.3 Parent knowledge scale—Parenting knowledge was measured using the 19-item knowledge scale from a larger questionnaire assessing various aspects of the parents' knowledge, efficacy, and behaviors (parent beliefs and behavioral questionnaire [PBQ]) for promoting learning and educational progress in school-age children with cancer. During development, the measure was piloted with 121 parents of healthy children in the community³⁴ and then revised with cancer-related items (PBQ-R) to examine the relationship between parent involvement and cognitive functioning in 56 CCSs.³⁵ Construct validity was further supported in a separate sample of 44 CCSs where scores on the parenting knowledge, efficacy, and "pro-learning" behaviors scales (PBQ-R2) improved as a result of a parent-directed intervention.³⁶ The PBQ-R2 parenting knowledge scale has good reliability (Cronbach's $\alpha = 0.94$) and good test-retest reliability (correlation of .84 with repeated assessment across at 3-month interval; $n = 44$).³⁶ The PBQ-R2 was translated to Spanish for this study following input from the advisory panel and pilot-tested with six Latino parents of children with cancer prior to use in this study. The measure is currently used in ongoing research with other samples of Hispanic families. The knowledge scale assesses the parent's knowledge of how to promote good study habits and help their child with learning. Parents responded to statements such as: "I know study strategies that may help my child with schoolwork"; "I know how to find resources to help my child"; "I know how to increase my child's motivation towards school work"; "I know how to help my child be more organized"; "I know my child's current learning and school needs"; "I know how to help my child at home with their learning and school work"; and "I know how to increase my child's persistence with schoolwork." Responses range from 1 (nothing) to 5 (a lot) with higher scores reflecting greater parenting knowledge.

1.2.4 Child academic motivation—This measure was developed for the purpose of this study based on models of academic motivation and self-determination, and were chosen to reflect school-related intrinsic motivation based on self-determination theory.²⁵⁻²⁷ It consisted of seven items, which were pilot tested and adapted for use with the study population. The measure asked parents about their child's motivation using the following statements: "My child tries hard in school"; "My child will adapt and find ways to cope with the challenging situations or materials presented at school"; "My child will seek out a sibling, family member or parent when s/he is confused or needs assistance in schoolwork"; "My child is able to seek out teachers or teacher's aides in order to keep up with class work"; "My child believes doing well in school will help them do better in life"; "It is important for my child to do well in school"; and "My child is able to seek out support from friends and classmates to keep up with class material." Responses ranged from 1 (strongly disagree) to 6 (strongly agree). Higher scores reflect greater child motivation. Factor analysis of the seven items indicated a single factor with loadings ranging from .66 to .88. These seven items showed good reliability ($\alpha = .92$).

1.3 Statistical analyses

Descriptive statistics were used to describe the child and parent/caregiver population and to summarize parents' responses on the study measures. A five-step multivariable linear regression analysis examined the contribution of psychosocial factors (i.e., parent education [an indicator of socioeconomic status], child motivation, and parenting knowledge) with the

child's school HRQOL as the dependent variable, *after* controlling for child's current age and cancer-related predictors of child's school outcomes (brain tumor versus leukemia; cancer diagnosis at age <6 years versus ≥6 years³⁷). The child's age at the time of data collection was entered in the first step, cancer-related variables in the second step, parent education in the third step, child motivation in the fourth step, and parenting knowledge in the final step. Parenting knowledge was entered last given our primary hypothesis that this variable is predictive of the outcome even after accounting for effects of the other predictors.

Household income was highly correlated with parent education, and the caregiver's language (Spanish vs English) was highly correlated with education level ($P < .01$); English-speaking parents had higher education and income. In addition, use of cranial radiation was highly correlated with brain tumor diagnosis (yes vs no), and time since cancer diagnosis was correlated with the child's age at diagnosis ($P < .05$); therefore, these variables were not included in the model to reduce multicollinearity. Unique and cumulative variance contributed by predictors was examined. All data were analyzed using SPSS 25.³⁸ The α -level for significance was set at $P = .05$.

2 RESULTS

Demographic and descriptive data for the CCSs and both their parents are presented in Table 1. Of the 73 caregivers who completed study measures, 56 were mothers, 13 were fathers, and four were other relatives. Fifty-six (77%) of the respondents completed the survey in Spanish. Of the 73 CCSs, 42 (57%) were male, 54 (74%) were diagnosed with acute leukemia, and 19 (26%) had brain tumors. The mean age of the CCSs at diagnosis was 5.0 years (SD 3.28, range 1-14) and at study participation was 12.0 years (SD 3.91, range 6-18), with a mean of 7.0 years (SD 3.18, range 1-15) since cancer diagnosis. Based on parental report, treatments included chemotherapy ($n = 67$, 92%), surgery ($n = 31$, 42%), radiation ($n = 15$, 20%), and bone marrow transplant ($n = 16$, 22%).

The majority of the mothers ($n = 59$, 83%) and fathers ($n = 57$, 85%) were born outside of the United States. Most of the families ($n = 55$, 75%) spoke primarily Spanish at home. The majority of mothers ($n = 67$, 92%) and fathers ($n = 65$, 89%) were employed. Three-quarters of mothers (75%) did not complete high school, and 45% of the families reported an annual income <\$20,000.

Parents' responses on the PedsQL school domain indicated the children were functioning at a significantly lower level (mean 62.29; SD 21.38) compared to the values reported for healthy children (mean 78.27; SD 19.64) ($P < 0.01$)²⁸ The mean child motivation score was 5.16 (SD 1.10; range 1-6) and the mean parental knowledge score was 3.72 (SD 0.66, range 2.24-5) with higher scores reflecting greater child motivation and parenting knowledge.

3.1 Multivariable analyses

Results from multivariable linear regression are displayed in Table 2. In step one, the child's age did not significantly contribute to the regression model and accounted for only 0.4% of the variation in school HRQOL. Introducing the cancer-related variables in step two explained an additional 14.3% of the variance, as brain tumor diagnosis and younger age at

diagnosis were associated with lower school HRQOL; this change was significant ($F(2,65) = 5.46, P < .01$). Adding parent education to the model in step three explained an additional 4.1% of variance in school HRQOL, and this change suggested trends toward significance where lower parent education was associated with lower school HRQOL, but did not reach the significance criterion ($F(1,64) = 3.25, P = .076$). At step four, adding child motivation to the regression model explained an additional 16.1% of the variance, where higher motivation was associated with better school HRQOL, and this change was significant ($F(1,63) = 15.60, P < .001$). For the final step, the addition of parenting knowledge explained an additional 4.7% of the total variance after controlling for all the other variables in the model, and this change was significant ($F(1,62) = 4.88, P < .05$). Higher parenting knowledge was associated with higher school HRQOL.

1 DISCUSSION

Our five-step multivariable regression model showed that the predictors in the model accounted for 40% of the variance in school HRQOL. As anticipated, the cancer-related factors (brain tumor diagnosis and younger age at cancer diagnosis) were significant predictors.^{10,39} In addition, the social-ecological variables of parent education level, child motivation, and parenting knowledge accounted for approximately 25% of the variance in school HRQOL in the expected direction. Further, the results supported our hypothesis that parenting knowledge is a contributor even after controlling for effects associated with the other variables in the model. While the parent education level suggested trends, it was not a significant predictor, probably because our sample is homogeneous with most parents having less than a high school diploma.

The current report is consistent with previous work from our research group. In our previous study of Hispanic CCSs, aged 8-18 years, parent-reported HRQOL was substantially lower in the school functioning domain for Hispanic CCSs compared to other ethnic minority and non-Hispanic White CCSs.¹⁶ In another study, we identified low parental acculturation as a strong predictor of worse child functioning, suggesting that social and cultural factors contribute to the survivor's functioning.¹⁷

Prior research suggests that healthy children's motivation predicts academic achievement^{24,25} and parental knowledge and involvement is associated with better school outcomes.^{40,41} However, to the best of our knowledge, this was the first study to identify these relationships in CCSs. Fortunately, both parenting knowledge and child motivation are modifiable social-ecological factors that can be increased through targeted intervention. In fact, child motivation is highly associated with parental values and parenting behaviors across populations, including among Hispanic families.^{42,43} Furthermore, child motivation can be enhanced by targeting parents when children are still young and more receptive to parental influences. We have incorporated these considerations in an ongoing intervention trial intended to improve children's school functioning among Hispanic CCSs.

Although we have identified novel predictors of school-related HRQOL in Hispanic CCSs, these results should be replicated and evaluated in other groups to determine whether these predictors are specific to Hispanic CCSs. Also, we encourage future research to incorporate

broader assessment of the social-ecological factors than was done in this study, as it is likely that there are other important aspects in the child and their environment that influence development after cancer.

Our study has other limitations that should be noted. The study was cross-sectional in nature; therefore, we cannot infer causation. To assess both the child's school HRQOL and motivation, we used parent-reported measures to reduce the burden of study participation on the family (i.e., not needing to bring their child in for assessment). In addition, the motivation measure was developed specifically for this study and requires further evaluation to establish validity. Cancer-related factors included in our regression were broad and did not include specific treatment dose as we did not have access to the medical records for the majority of children whose parents participated in this study. Using parent-report data, cranial radiation and brain tumor were highly correlated and so only one of these was included in our regression model; it is possible that the inclusion of more specific detail, such as radiation dose, may have been informative. Furthermore, this study evaluates Hispanic families in the Los Angeles area, and it is not clear whether the current results will extend to Hispanic families living in other locations or to other demographic groups. Despite these limitations, this study contributes to the sparse literature to help clinicians and researchers understand noncancer-related, social-ecological influences on CCSs' outcomes, particularly in a high risk, socioeconomically disadvantaged group.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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TABLE 1

Parent and child demographic characteristics

Child information	N		Percentage	
Age in years	12.01 (3.91) ^a		6-18	
Gender				
Male	42		58	
Female	31		43	
Type of diagnosis				
Brain tumor	19		26	
Acute leukemia	54		74	
Age at diagnosis (years)	5.03 (3.28) ^a		1-14	
Time since diagnosis (years)	7.06 (3.18) ^a		1-15	
Treatment received				
Chemotherapy	67		92	
Surgery	31		43	
Radiation	15		21	
Bone marrow transplant	16		22	
Parent information	Mother		Father	
	N	Percentage	N	Percentage
Age in years	39.58 (6.52) ^a	26-56 ^b	41.45 (7.23) ^a	28-57 ^b
Marital status				
Single	9	13	3	4.7
Married/living as married	55	79	52	81
Other	6	8.5	9	14
Education				
No school	19	28	14	23
<High school diploma	33	48	28	47
High school graduate	14	20	9	15
Some college	3	4.3	9	15
Family annual income				
0-9999	13	18		
10 000-19 999	20	27		
20 000-49 999	34	47		
50 000-74 999	6	8.2		
75 000	0	0		
PedsQL school domain scaled score	62.29 (21.38) ^a	10-100 ^b		
Parent perceived child motivation	5.16 (1.10) ^a	1-6 ^b		
Parental knowledge	3.72 (0.66) ^a	2.24-5 ^b		

^aMean (SD).

b_{Range}

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TABLE 2

Hierarchical regression analyses predicting school HRQOL functioning (N = 73)

Predictor	B	SE _b	β	P-value	R ²	R ²
Step 1:					.004	.004
Child's age	0.331	0.668	0.061	.622		
Step 2:					.147	.143**
Brain tumor	-12.880	4.714	-0.274	.008		
Age at diagnosis	-13.813	5.348	-0.316	.012		
Step 3:					.188	.041
Parents' highest level of education	0.793	1.151	0.072	.493		
Step 4:					.349	.161**
Child motivation	7.192	2.022	0.382	.001		
Step: 5					.397	.047*
Parenting knowledge	7.505	3.399	0.228	.031		

Abbreviations: B, unstandardized coefficient; β = standardized coefficient.*
P < .05**
P < .01.