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A parent-directed intervention for addressing academic risk in Latino survivors of childhood leukemia: results of a pilot study

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Introduction

Acute lymphoblastic leukemia (ALL) is the most common form of childhood cancer [1]. Although approximately 90% of patients become long-term survivors, up to 40% may develop treatment-related neurocognitive dysfunction that impairs learning and school performance [1–3]. Consequently, routine neuropsychological screening is recommended by the Children’s Oncology Group (COG Long-Term Follow-Up Guidelines) for all childhood ALL survivors [4]. However, low socioeconomic status (SES) is associated with lower cognitive and academic functioning [5] and is hypothesized to exacerbate treatment-related neurocognitive deficits [6]. Because low SES is over-represented in Latinos and other minority groups, lower academic function can appear more pronounced in these cultural settings. Further, cultural, language and literacy differences may adversely impact care and participation in research [7]. Because a large proportion of childhood ALL survivors at our institution are challenged by all these factors, we developed an innovative psycho-educational intervention to improve academic success in this population and report here our favorable pilot experience.

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Conflict of interest

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Supporting information

Additional supporting information may be found in the online version of this article at the publisher’s web site.

Methods

General description

This clinical service comprises a parent-directed intervention to increase academic support for school-aged survivors of childhood ALL. Although the service is available to every childhood ALL survivor because of treatment-related risk for neurocognitive dysfunction, it incorporates key elements of cultural and linguistic competency [8] to address common barriers facing the substantially Latino, urban, and low SES population treated at our institution (Table S1). Services and information are provided in Spanish, when appropriate, by a bilingual/bicultural psychologist. Data collection was approved by our Institutional Review Board (IRB); written informed consent/assent covering this project was obtained as part of our ongoing IRB-approved cancer survivorship database mechanism that permits analytical use of any data that are collected for purposes of routine care.

Study objectives and design

This is a non-randomized, prospective cohort pilot study designed to (1) assess the feasibility and preliminary efficacy of a clinical service routinely provided at our institution and (2) determine predictors of participation.

Participants and recruitment

All childhood ALL survivors currently in kindergarten-12th grade who are undergoing their first comprehensive evaluation in our cancer survivorship clinic were eligible to receive the complete service described herein. Parents and children were routinely educated by the clinical survivorship team regarding treatment-related factors that increase the survivor's risk for neurocognitive dysfunction. All parent-child dyads were then recruited by the child psychologist through reinforcement of risk factors and invitation to utilize the service. Although cultural competency was focused on the predominantly Latino composition of our patient population, the service was open to survivors of any race/ethnicity to receive the general benefits of academic support.

Procedures

The intervention was delivered over two encounters. Herein, the term "intervention" is used to encompass both of these encounters. Participants are defined as those who chose to receive the intervention. At the first encounter, cognitive, academic, and socioemotional functioning was assessed by standardized measures requiring about 4 h to administer (Table S2); parents completed surveys describing demographics, language preferences, SES characteristics, and parental knowledge, attitudes, behaviors, and self-efficacy related to their child's education. Regardless of prior cancer treatment exposures, dyads were then assigned either to the standard or tailored (i.e., more comprehensive and individualized) intervention based principally on psychoeducational assessment results (standardized cognitive test results that were ≥ 1.0 standard deviation below the normative mean in two or more areas such as intelligence, verbal memory or executive functioning; and/or (2) test performance below grade level in math and reading comprehension). In interpreting verbal-based test results, allowance was made for English language development in bilingual

children. In the second encounter, all dyads attended a feedback session, which constituted the standard intervention, to receive psychoeducational assessment results and general recommendations for academic support. Dyads assigned to the tailored intervention received the basic information constituting the standard intervention, but in addition received augmented and personalized advocacy training for securing additional school, community, or home-based resources, lasting approximately 2 h. Our emphasis was on skills-training to empower parents as effective advocates using extensive oral teaching supplemented by bilingual, plain-language handouts, as well as “teach back” of key points and scenarios to anticipate upcoming challenges when interacting with their schools (Table S1). Parents of all participants, regardless of intervention level, completed a five-item Likert-scale satisfaction survey. The intervention was designed to be completed within approximately 4–6 weeks from recruitment, although flexibility was offered to accommodate family needs. Within 4 weeks, the psychologist contacted the parent to assess follow-through on recommendations made. Additional information and suggestions were provided at that time or whenever requested.

Statistical analysis

Patient characteristics were compared between those who elected (participants) or declined (non-participants) to participate in the psychoeducational intervention using the χ^2 test for categorical variables or logistic regression for continuous variables. Characteristics having a *p*-value of <0.15 in Table 1 and Table S3 were entered into a preliminary multivariate model to predict participation. Through reverse step-wise selection, predictors with a likelihood ratio test *p*-value<0.05 remained in the final multivariate model. This approach was validated by assessing changes in significance through reintroduction of eliminated predictors. Because parent language is highly correlated with race/ethnicity and all parents who declined participation were non-Spanish speaking, the stratified Mantel–Haenszel test was used to investigate the effects of maternal language and verified using 10,000 replicate permutation testing. All *p*-values are two-sided with <0.05 used to define significance. Statistical computations were performed using Stata.

Results

Clinical, sociodemographic, and treatment characteristics of our cohort are shown in Table 1 and Table S3. Multiple parental risk factors relevant to academic performance were identified, including limited English fluency, education, employment, and income. Many of those risks were less frequent among non-participating dyads.

Completion of intervention and predictors of participation

Of 63 eligible dyads, 49 (77.8%) elected to participate. Among the participants, a very high level of engagement was noted across the standard and tailored interventions, as 48/49 (97.9%) completed both encounters. Thirty-two of 49 participants (65.3%) met criteria for tailored intervention. The high level of participant engagement is characterized in Table S4 and implies acceptability of intervention procedures, including psychoeducational assessments. Non-participants tended to be older, non-Latino, and privately insured (Table 1 and Table S3). By multivariate regression analysis, White/non-Hispanic and those of other

race/ethnicity were less likely than Latinos to participate (odds ratio [OR] 0.06; 95% Confidence Interval [95%CI] 0.004, 0.88 and OR 0.01; 95%CI 0.001, 0.17, respectively). Compared with patients in elementary school, high-schoolers (9th–12th grade) were less likely to participate (OR 0.03; 95%CI 0.003, 0.31). Additionally, patients with Spanish-speaking mothers were more likely to participate ($p<0.001$).

Outcomes

Follow-up as reported by parents 4-weeks post-intervention is summarized in Table 2. Even at that early time point, the majority had already followed through on several recommendations to increase or enhance academic support services or activities, including relatively complex tasks such as requesting an IEP evaluation.

A post-intervention survey of participating parents found that the vast majority learned new information, anticipated increased school success, had higher academic expectations for their child and were satisfied with what they learned. However, parents perceived that deficits in their own English proficiency and educational levels limited improvement in managing their child's homework (Table S5).

Discussion

Our results provide insight into the multiple yet sometimes underappreciated neurocognitive risks facing disadvantaged populations of childhood ALL survivors. In this pilot study, we have described a feasible approach for addressing such risks using a culturally and linguistically competent intervention that yielded high levels of patient/parent engagement, early indicators of follow-through, and parental satisfaction. Our findings are consistent with those of a recently published study that found over 90% of Latino parents of childhood cancer survivors expressed interest in a culturally competent intervention aimed at reducing neurocognitive late effects [9]. Our intervention is based on the premise that neurocognitive assessment should be a standard component of survivorship care for at-risk patients, and that it plays a crucial role in addressing immediate school needs, as well as longer-term educational, vocational, and employment outcomes [2–4,10]. We believe that the critical ingredient of our approach is its culturally competent design and implementation (Table S1), which includes a culturally and linguistically competent psychologist. All parents who chose not to participate were non-Spanish speaking. It is difficult to separate completely the effects of language differences from those of race/ethnicity and SES. It is also possible that our focus on Latino cultural competency itself could have influenced the choice by other groups not to participate. In the selection of measures used in our psychoeducational assessment, we sought to balance comprehensiveness with testing time required of resource-challenged families. The importance of emotional/behavioral functioning in academic performance is acknowledged, and consideration could be given to weighting this more heavily through inclusion of additional formal measures.

Currently, our psychologist is funded through a foundation grant. Although this may represent a challenge for some institutions, we feel that high-volume treatment centers like ours treating many Latino patients have an obligation to pursue the highest possible standards of survivorship care, which includes cultural competency in delivering vital

academic support. To achieve long-term financial sustainability for this service, our center is pursuing enhanced billing and reimbursement practices. Having shown the feasibility and acceptance of our approach in this pilot study, evaluation of its impact will require a randomized clinical trial to gain a more complete understanding of factors affecting participation and to compare this intervention with usual practice, including longitudinal data collection on academic outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key points

- Survivors of childhood acute lymphoblastic leukemia are at risk for treatment-related neurocognitive dysfunction, which may be exacerbated by factors related to low socioeconomic status and linguistic disparities.
- Approximately, half of childhood lymphoblastic leukemia survivors at our institution are Latino and exhibit multiple socio-demographic risk factors that threaten academic functioning.
- To better serve these survivors, we developed a culturally competent, parent-directed intervention to improve academic success that is feasible to deliver, shows preliminary evidence of efficacy, and is valued by families.
- The approach outlined here enables pediatric cancer treatment centers to provide culturally competent assessment and academic support that exceed published guidelines for survivors at neurocognitive risk.

Table 1.Cohort characteristics ($n = 63$)

	Participants ($n = 49$)	Non-participants ($n = 14$)	<i>p</i>
Patient information			
Age, years (range)			
Mean, at diagnosis	4.9 (1.2–12.6)	7.4 (1.0–15.2)	0.012
Mean, at time of service	10.9 (5.2–18.1)	14.5 (8.0–18.5)	0.001
Mean time interval post-treatment, years (range)	3.2 (0.3–14.1)	4.2 (1.0–11.0)	0.244
Sex			
Male	23 (46.9)	11 (78.6)	0.036
Female	26 (53.1)	3 (21.4)	
Race/ethnicity			
White/non-Hispanic	3 (6.1)	3 (21.4)	0.001
Latino	44 (89.8)	6 (42.9)	
Asian	2 (4.1)	4 (28.6)	
African-American	0 (0)	1 (7.1)	

Bolded *p*-values indicate those that are statistically significant.

Table 2.

Reported completion of recommendations by 4-weeks post-intervention (*n* = 49)

Action, resource, or referral	Recommended ¹ <i>n</i> (% of all participants)	Completed <i>n</i> (% of those recommended)
School-focused		
Initiate educational support program (e.g., IEP or 504)	22 (44.9)	14 (63.6)
Request enhancement of existing services	7 (14.3)	7 (100)
Request additional school resources	15 (30.6)	5 (33.3)
Community-focused		
Enrichment activities (e.g., art, music, and sports)	25 (51.0)	11 (44.0)
Legal advocacy referral	3 (6.1)	3 (100)
Mental health services		
Limited intervention by service psychologist	5 (10.2)	4 (80.0)
Mental health referral		
Community site	22 (44.9)	7 (31.8)
Within institution	6 (12.2)	2 (33.3)

¹Recommendations not mutually exclusive; two or more made for some patients.