

Parental Advocacy in the School System for Pediatric Survivors of Acute Lymphoblastic Leukemia (ALL): Teaching Parents with Low Literacy to Apply Health Knowledge

Laura Bava, PsyD, Christopher Nuñez, PhD, Betty-Gonzalez-Morkos, PsyD, Lisl Schweers, LCSW, Maki Okada, RN, MS, CPNP, Kathy Ruccione, MPH, RN, FAAN, Ernest Katz, PhD, and David R. Freyer, DO, MS

Introduction/Background

- Children treated for ALL are at increased risk for poor academic and health outcomes as a result of curative treatment. Survivors from ethnic minorities and lower SES are particularly at risk due to additional socio-demographics factors.
- To best address the multifaceted needs of survivors of childhood and adolescent cancer, multidisciplinary teams that emphasize prevention, education, and advocacy are essential (Children's Oncology Group, 2008)
- Despite increased risk for underserved populations, these groups are infrequently included in research of survivors of childhood ALL due to language or literacy barriers.
- ALL survivors' post-treatment difficulties at school are often not addressed due to parental deficits in knowledge, skills and resources needed to navigate the complex educational system.
- Navigating the health and educational systems post-treatment can be daunting among the overall population, especially for those facing additional barriers.
- Additional psychosocial difficulties commonly faced by Latino parents include limited literacy and limited English proficiency (15.3 million people in the U.S. (ages 18-44) speak Spanish at home (U.S. Census Bureau, 2011).
- The ABCs service was launched to develop an effective approach for increasing academic success of childhood ALL survivors at the LIFE Cancer Survivorship & Transition Program at CHLA.

Methods

- Target population: School-Age (K-12th) ALL and Lymphoblastic non-Hodgkin Lymphoma (NHL) survivors
- Research: Data acquisition for future outcomes research and program evaluation
- Service delivered in 3 encounters: Initial survivorship medical clinic visit, detailed psycho-educational assessment, and feedback and intervention

ABCs Service Model Key Elements



Providing Culturally and Linguistically Competent Services

- Providers need to be aware of effect of bilingualism on cognitive and academic functioning (Rivera-Mindt et. al 2008).
- There are 1.4 million English learners in California, 25% of whom are not fluent in English (California Department of Education, 2009)
- Low levels of literacy (in Spanish and/or English) and English language proficiency are commonly present (U.S. Census Bureau, 2011) for Latino parents. Thus, many families have difficulties reading and understanding written materials.

Challenge	ABCs Approach/Solution
Health & Educational Disparities	• Emphasis on providing culturally and linguistically competent service, including attention to health literacy and language barriers.
Language Barriers	• Service provided by bilingual (Spanish) psychologist • Parental measures available in Spanish • Educational and community resources handouts available in Spanish
Low Literacy	• Awareness of literacy barriers at play. Assistance with completing measures (e.g., read to parents)
Transportation and financial challenges	• Flexibility on scheduling appointment with other hospital services • Reduced number of visits.
General "one size fits all" clinical approach	• Highly individualized and resource-intensive approach. • Patients receive standard or tailored intervention based on their specific cognitive, academic and psychosocial needs as indicated by a pre-established composite cut off of administered measures.

Results

Table 1. Selected Psychosocial Characteristics

Patient Characteristics		% (n)
Race/Ethnicity	Latino/a	90 (43/48)
Sex	Female	54 (26/48)
Grade	K -5 th grade	67 (32/48)
English proficiency	Limited (CALP 3-3.5)	76 (25/33)
Age	Mean = 10 (s.d. = 3.2)	Range = 5-18 years
Interval post treatment	Mean = 3 years (s.d. = 2.4)	Range = 0.7 m.- 14 y.
Caregiver Characteristics		% (n)
Preferred language	Spanish	56 (27/48)
Education level	Middle school or less	50 (24/48) mothers
	Middle school or less	45 (20/44) fathers

Table 2. Service Progress Highlights

75 % (48/64) of patients recruited participated in the ABCs service
98% (47/48) of participants completed the entire service
67% (32/48) of those assessed needed tailored intervention
44% (21/48) of patients were recommended to request formal educational support
15% (7/48) of patients were advised to request modifications to existing services
Many parents had difficulties completing self-report and written measures and required assistance

Conclusions/Discussion

- This service builds on existing comprehensive and systematic long-term follow-up care for ALL and NHL survivors seen at the LIFE clinic.
- Our experience indicates that navigating the educational system is complex and families benefit from improving their knowledge, skills and resources.
- Providing culturally and linguistically competent services begins by addressing language barriers, but must also go beyond to identify and report socio-economic factors, including barriers for participation due to low literacy levels.
- Despite emphasis on cultural competency, our service can benefit from additional strategies to address low levels of literacy and assist parents successfully navigate school and health systems for their children. Possible strategies can include:
 - Assessment of parental literacy in a formal, standardized manner
 - Development/Use of audiovisual materials for parents to review taught concepts on their own
 - Development/use of reading materials designed for low literacy audience
 - Development of a curriculum based group training brief program including: additional training sessions to help parents master information
 - Development of a navigator program using peer support/expert parents.
- Research component will continue to inform clinical practice

Funding provided by a private foundation

Selected References:

- Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. <http://www-survivorshipguidelines.org/>
- Rivera Mindt, M., Arentoft, A., Germano, K. D'Aquila, E., Scheiner, D., Pizzirusso, M., Gollan, T. (2008). Neuropsychological, cognitive, and theoretical considerations for evaluations of bilingual individuals. *Neuropsychology Review*, 18, 255-268
- Sanders, L.M., Shaw, J.S., Guez, G., Baur, C., & Rudd, R. (2009). Health literacy and child health promotion: implications for research, clinical care and public policy. *Pediatrics*, 124, 306-314
- U.S. Census Bureau (2011). "2010 Census Briefs." Retrieved 12/01/2012, from <http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf>