

BRIEF REPORT

Measurement of Socio-Economic Status in Families of Children with Cancer in Guatemala

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The prospects for survival of children in low and middle income countries are linked to their families socio-economic status (SES), of which income is only one component. Developing a comprehensive measure of SES is required. Informed by clinical experience, a 15-item instrument was designed in Guatemala to categorize SES by five levels in each item. Almost 75% of families attending the Unidad

Nacional de Oncología Pediátrica were in the lowest three of six categories, providing a framework for stratified financial and nutritional support. The measure of SES offers an opportunity for examining associations with health outcomes throughout Latin America. *Pediatr Blood Cancer* 2014;61:2071–2073.

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Key words: cancer; children; measurement; socio-economic status

INTRODUCTION

Poor socio-economic status (SES) in their families is an important contributing factor to the compromised survival of children with cancer in low and middle income countries (LMICs) [1]. Among the mechanisms that connect poor SES with compromised health outcomes are under-nutrition [2], treatment-related morbidity and mortality [3] (TRM), and abandonment of therapy [4]. Identification of families who are most at risk would allow the use of interventions to reverse under-nutrition [5], reduce TRM [6] and minimize abandonment of therapy [7]; all leading to a diminution of treatment failure with improved prospects for cure.

Guatemala is the most populous country (total population more than 14 million) in Central America, and, with an annual *per capita* income of US\$ 2,740 in 2010, has been categorized as low middle income by the World Bank [8]. However, it has been estimated that 15% of the population live in extreme poverty [9] and there is marked income maldistribution; the wealthiest 10% accounting for 47% of the income consumption while the poorest 19% account for only 1% [10]. Of course there is more to SES than income and a consequent need to include other important contributory elements, such as the types of housing, water supply and sanitation. To that end an instrument has been developed for the measurement of SES in the families of newly diagnosed children with cancer in Guatemala. As the original instrument is in Spanish, it should be applicable, with modest local modifications, throughout most of Latin America and Mexico.

METHODS

Based on clinical experience, the staff at the Unidad Nacional de Oncología Pediátrica (UNOP) in Guatemala City designed a 15-item instrument with five ordinal levels in each item to capture a broad array of information pertaining to SES. The 15 domains are: Income according to social status; number of occupants living in the home who are employed; highest level of education of the head of the family; status of the dwelling; construction of the dwelling; mode of sanitation; means of communication; distance from/mode of transport to UNOP; family income per month; source/cost of water supply for drinking; source/cost of lighting; cost of food per month; types of resource for education and available/expenditure on

children's education; source of medication in the family; expenditure on recreation per month. Summative scores range from 15 (high) to 75 (low/poor SES). The instrument is provided in English and Spanish in the Supplementary Material. The questionnaire was completed in a mean time of 15 minutes. Families were categorized into six groups of SES: high (score 15–20), medium high (21–25), medium (26–30), medium low (score 31–45), low (46–60), and extremely low (61–75). In order to identify the families in need of support, and to provide effective interventions, the width of the ranges of scores was skewed purposefully to accommodate those with more compromised SES. The assignment of scores was accomplished by social workers and psychologists in interviews with families. It was intended to capture information on the families of all newly diagnosed children during the calendar year 2012 (n = 406).

RESULTS

The information on age, sex, and disease, according to the International Classification of Childhood Cancer [11], is provided in Table I. The interviews were completed on all families. Categorization of SES yielded the following distribution: High 6 (1.5%); medium high 22 (5.4%); medium 98 (19.2%); medium low 116 (28.6%); low 145 (35.7%); extremely low 39 (9.6%). Almost 75% of the families were in the lowest three categories. Based on this categorization, a policy of social support has been enacted, focusing on meeting financial expenses and the provision of food (Table II). This template provides the framework for the distribution of resources by the social workers.

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

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TABLE I. Age, Sex, and Disease Classification^a of Children With Cancer in Guatemala, UNOP, January 1–December 31, 2012

Disease classification	Number of children
Leukemias (including MDS)	183 (including 152 ALL, 25 AML)
Lymphomas	43 (27 Hodgkin, 16 non-Hodgkin)
CNS neoplasms	23
Neuroblastoma	4
Retinoblastoma	25
Renal tumors	16
Hepatic tumors	14
Malignant bone tumors	19 (11 osteogenic, 8 Ewing sarcomas)
Soft tissue sarcomas	27 (17 rhabdomyosarcoma)
Germ cell tumors (non-CNS)	30
Other malignant epithelial neoplasms and malignant melanomas	4
Other and unspecified malignant neoplasms	7
Langerhans cell histiocytosis	7

MDS, myelodysplastic syndrome; AML, acute myeloid leukemia; CNS, central nervous system. Age: 0.2 to 21, median: 7.6 years; sex: male/female = 225/181 (1.24). ^aInternational Classification of Childhood Cancer.

DISCUSSION

There are several mechanisms that appear to connect poor SES with compromised health outcomes in children with cancer in LMICs. As examined in Central America, these include undernutrition (severe malnourishment affecting the majority of these children at diagnosis [2]); treatment-related mortality (incurred in approximately 10% of children with acute lymphoblastic leukemia [ALL] [6]); and abandonment of therapy that was encountered formerly in almost half of the children in some countries, representing the commonest cause of treatment-failure in many LMIC [12]. In some circumstances these mechanisms may be interdependent [2].

Attention to nutritional deprivation during therapy for children with ALL in Guatemala has been associated with better outcomes [5]. Likewise, the rate of TRM in children with ALL has been reduced by 50% in adjoining Honduras [13], having been more than 20%, through improvements in supportive care and increasing familiarity with the treatment protocol [6]. The importance of attention to the numerous components of supportive care in children with cancer in LMIC cannot be over-emphasised [14]. By addressing the needs of severely disadvantaged families, the rates of abandonment of therapy in children with cancer in Central

America have been reduced dramatically, now to less than 2% in Guatemala and neighboring El Salvador [15].

Measurement of SES in families living in LMICs is clearly an important undertaking, as exemplified in the impact of socio-economic inequality on health from the World Health Surveys [16]. A focus on the association between SES and children's health has been the subject of several studies using different instruments in India [17]. Earlier studies than ours in Guatemala have identified the relationship between social inequality and children's growth [18] and, more recently, the need to target food fortification programs more effectively for the poor, defined by a household income expenditure survey [19].

A detailed study by Steele [20] provides some validation for the categories of SES developed for our study. That study examined water, sanitation and electricity services; level of education; home size and ownership, but not the quality of construction; in addition to earnings. Curiously, access to health services was not included. In her investigation Steele categorized 66% of Guatemalans as living below the poverty line and 38% as being extremely poor; with corresponding figures of 87% and 61% for the indigenous population. Our findings of 73% and 45%, respectively, using more than financial factors, appear to have face validity for UNOP

TABLE II. Social Support for Families of Children With Cancer in Guatemala

SES ^a	Program of support				
	Family food bag ^b	Money for travel	Food for caregiver ^c	Inn for families	Funeral assistance
High	No	No	No	No	No
Medium high	No	No	No	Yes ¹	No
Medium	Yes ¹	Yes ¹	Yes ¹	Yes ²	Yes ¹
Medium low	Yes ³	Yes ⁴	Yes ⁵	Yes ⁶	Yes ⁷
Low	Yes ³	Yes ⁹	Yes ⁵	Yes ⁶	Yes ¹¹
Extremely low	Yes ⁸	Yes ⁹	Yes ¹⁰	Yes ⁶	Yes ¹¹

^aSES, socio-economic status. ^bFood bag = Two pounds of oats, 5 pounds of beans, 5 pounds of rice, 5 pounds of sugar, 2 pounds of spaghetti and 4 pounds of incaparina (a mixture of maize and soy flours supplemented with vitamins and minerals, available commercially in Guatemala). ^cFood for caregiver while child is an inpatient. Yes¹ = sometimes. Yes² = frequently. Yes³ = every 15 days. Yes⁴ = one way or return. Yes⁵ = once a day. Yes⁶ = always, unless living near to hospital. Yes⁷ = some assistance. Yes⁸ = every week or clinic appointment. Yes⁹ = return journey. Yes¹⁰ = thrice daily. Yes¹¹ = all expense covered.

provides care free of charge and so caters to a relatively disadvantaged segment of Guatemalan society.

In continuing studies, involving considerably more families, we are examining the correlations between SES and rates of under-nutrition at diagnosis, early TRM and abandonment of therapy, as well as assessing the efficacy of the financial and nutritional interventions. Application of our measurement tool in other Spanish-speaking societies in the New World is encouraged and should provide further guidance with respect to the need for social supports that could improve the health outcomes in children with cancer in these countries.

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