Understanding the unique social determinants of quality of life and research inclusion in young adult cancer survivors: preliminary findings

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Abstract

Adolescents and young adults (AYAs) with cancer, defined by the National Cancer Institute as individuals between the ages of 15 and 39 at diagnosis, are a unique subpopulation on which comparatively little research attention has been paid. Although differences in survival among AYA diagnosed with cancer have been found to vary with neighborhood socioeconomic status (SES), few studies have focused on specific individual-level barriers which may face this demographically diverse population. The following presents preliminary findings from the Socioeconomics and Quality of Life (SEQOL) study, a questionnaire-based study designed to elicit individual socioeconomic factors which may enhance or buffer the myriad of adverse consequences of being diagnosed with cancer during young adulthood. Results from focus groups and interviews with a subset of these patients will augment the discussion on the findings from the quantitative analyses. In addition, results of survival analyses conducted using California Cancer Registry data to investigate the effect of neighborhood SES will also be presented. Socioeconomic disparities appear to adversely influence survival of adolescents and young adults with leukemia and lymphoma independently of race, ethnicity, gender, and several clinical parameters. The SEQOL study intends to examine the specific factors that might contribute to these disparities.

Background

- Socioeconomic status (SES) = *"social and economic factors that influence which positions individuals or groups will hold within a structure of a society"* (Galobardes et al., 2006)
- Adolescent and young adult (AYA) patients with cancer have recently been recognized as an underserved group by the National Cancer Institute's Adolescent and Adult Oncology Progress Review Group, and found to have:
  - Lower enrollment on clinical trials than all other age groups (Bleyer, 2007)
  - Lower rates of having health insurance than all other age groups (Ward et al., 2008)
  - Reduced access to regular care and delays in diagnosis as compared to pediatric patients (ages 0-14) (NCI AYAO Progress Review Group, 2006)
  - Ultimately lower survival than pediatric patients (ages 0-14) (Bleyer et al., 2006, Kent et al., 2009)
- Two of the most common cancer types in the AYA population are leukemia (approximately 5-12%) and lymphoma (approximately 18-24%) (Bleyer et al., 2006)
- Two important research areas have emerged:
  1. *Disparities in Survival:* Little research has been conducted on the influence of SES on cancer outcomes in AYAs to identify possible socioeconomic disparities in cancer survival within this age group
  2. *Unique Survivorship Experiences:* We have much to learn about the unique challenges of both surviving cancer as a young adult and thriving as a survivor; survivor voices must be an integral part of the research on young adult cancer experiences

The Socioeconomics and Quality of Life (SEQOL) Study

1. To examine whether there are age-group, race/ethnic, and neighborhood socioeconomic effects on overall survival and cancer-specific survival for leukemias and lymphomas in individuals who were diagnosed between 1996 and 2005 in California

2. To investigate individual social circumstances and their effects on two aspects of survivorship (health-related quality of life and participation in cancer clinical trials) in AYAs ages 18-39 with leukemia and lymphoma through a population-based questionnaire study

3. To partner with AYA survivors to further explore the unique challenges and issues facing this population through a series of research dialogue groups

Aim 1: Cancer Registry Analysis

Methods:

California Cancer Registry (CCR) data were analyzed to determine whether neighborhood SES (nSES) affects survival above and beyond other demographic (gender, race/ethnicity) and clinical (histology, stage at diagnosis) factors for leukemia and lymphoma cases diagnosed between 1996-2005.

- nSES measured with a composite index called "**QUINYOST**" (Yost, 2001) at census block group of residence at diagnosis (*Factor loadings in parentheses*)
  - **Measures of Occupation:** proportion of population with blue-collar job (-0.70); proportion of population >16 in workforce but unemployed (-0.68)
  - **Measures of Income:** median income (0.85); proportion below 200% below poverty level (-0.87)
  - **Measures of Education:** educational attainment (Liu Index) (0.87)
  - **Adjustment, Cost-of-Living:** median rent (0.63); median house value (0.78)

Statistical Analysis:

- Demographic characteristics and clinical parameters: Pearson's χ^2 test, Fisher's exact test, or Kruskal-Wallis test for continuous variables
- Life tables and Kaplan-Meier curves will be generated for age group, race/ethnicity, SES categories, and insurance status, and curves will compared with the log-rank test
- Cox proportionate hazard regression will be performed to generate adjusted hazard ratios (HRs) for overall survival (OS) and leukemia-specific survival (LSS) and lymphoma-specific survival

Selected Results:

Figure 1. Kaplan-Meier survival curves of nSES on overall survival time in AYAs (18-39) with leukemia*. Data from the CCR, years of diagnosis: 1996-2005. *N* = 2,782

Legend: Highest SES, High SES, Middle SES, Low SES, Lowest SES
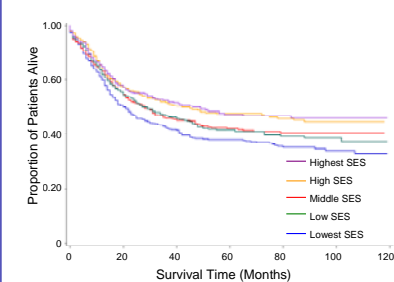
*Patients with Chronic Lymphoblastic Leukemia (CLL) were excluded from analysis.

Figure 2. Kaplan-Meier survival curves of nSES on overall survival time in AYAs with lymphoma. Data from the CCR, years of diagnosis: 1996-2005, *N* = 7,042.

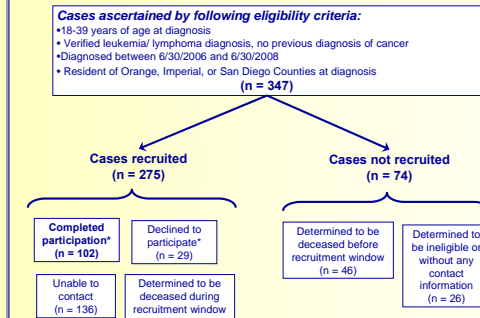Legend: Highest SES, High SES, Middle SES, Low SES, Lowest SES
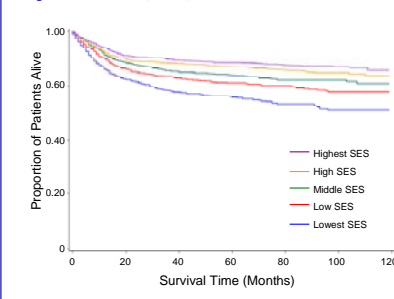
Aim 2: Questionnaire Study

Methods:

Cases recently diagnosed in Orange, San Diego, and Imperial counties in California were sent the SEQOL questionnaire to assess individual socioeconomic factors, based on Oakes & Rossi's CAPSES measure, which contains items related to the components of human, material, and social capital. The questionnaire data are being analyzed to see whether CAPSES is significantly related to attitudes toward participation on clinical trials, wait time between diagnosis and treatment, stage at diagnosis (lymphoma only), whether participants received treatment at research based institutions, and quality of life. First, correlations between neighborhood measures (nSES) and individual measures (iSES) were measured and are presented here.
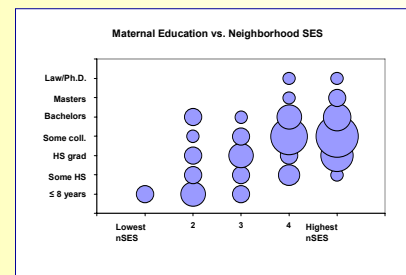
Figure 3. Case ascertainment and recruitment

Cases ascertained by following eligibility criteria:
- 18-39 years of age at diagnosis
- Verified leukemia/ lymphoma diagnosis, no previous diagnosis of cancer
- Diagnosed between 6/30/2006 and 6/30/2008
- Resident of Orange, Imperial, or San Diego Counties at diagnosis
(n = 347)

Cases recruited (n = 275)
- Completed participation* (n = 102)
- Declined to participate (n = 29)
- Unable to contact (n = 136)
- Determined to be deceased during recruitment window (n = 8)

Cases not recruited (n = 74)
- Determined to be deceased before recruitment window (n = 46)
- Determined to be ineligible or without any contact information (n = 26)

*No significant race/ethnicity or nSES between participants and decliners

Selected Results: Correlation Matrix of nSES and iSES indicators

	nSES	Self-Reported Social Class	Education	Maternal Education	Paternal Education	Income	Household Net Worth
nSES	1.00						
Self-Reported Social Class	0.48	1.00					
Education	0.38	0.26	1.00				
Maternal Education	0.28	0.23	0.47	1.00			
Paternal Education	0.17	0.41	0.32	0.50	1.00		
Income	0.34	0.64	0.28	0.20	0.13	1.00	
Household Net Worth	0.47	0.62	0.34	0.23	0.25	0.79	1.00

= significant at $P < 0.05$

Figure 4. Bubble graph showing overlap of nSES and a selected iSES indicator*

Maternal Education vs. Neighborhood SES

(Y-axis: Law/Ph.D., Masters, Bachelors, Some coll., HS grad, Some HS, ≤ 8 years; X-axis: Lowest nSES, 2, 3, 4, Highest nSES)

*Size of bubbles relates to the number of participants who responded to each category.

Aim 3: Focus Groups

Methods:

- Using a local survivor network called i2Y ("I'm Too Young for This") and patient records from an oncologist who specializes in the AYA population, I invited members to participate in qualitative research discussion groups. The format was open-ended and structured around the following question:

What do scientists, doctors, and the general public *not* understand about adolescent and young adult cancer experiences?

In lieu of asking leading questions, such as "which people provided you the most support after your cancer diagnosis: your friends, family, healthcare providers, or other survivors, and why?", much more open-ended questions such as "what kinds of support structures were available/ did you rely on after your cancer diagnosis?" were favored.

Preliminary Results: Selected emerging themes

- life interruption
- treatment management & coping skills
- chance to re-evaluate values and priorities
- change in social connections
- fertility and child-bearing/raising challenges
- challenges in obtaining/ maintaining health insurance
- need for awareness among community
- unique from "pediatric" and "geriatric" populations

Figure 5. A word cloud depicting common themes that have emerged from these dialogue groups*

*Size of the word corresponds with its use frequency

Conclusions & Next Steps

The California Cancer Registry is the largest regional registry in the world; large number of cases with sufficient statistical power to study specific AYA cancers, however no individual SES (iSES) is systematically collected. Neighborhood SES (nSES) appears to contribute to disparities in survival; however, it does not correlate exactly with measures of iSES, which may be an even stronger measure. Further, the impact of nSES on survival has been shown to vary by race/ethnicity in AYA cancer patients (Kent et al., 2009, Kent et al., *In Prep*).

Future directions:
1. Complete the questionnaire analysis to determine the effect of individual SES on health-related quality of life (HRQOL) and attitudes toward cancer clinical trials.
2. Conduct a multi-level analysis on individual and neighborhood SES effects on HRQOL and survival.
3. Compare attitudes toward cancer clinical trials between AYA cancer survivors and healthy young adults from an on-going web-based survey.
4. Using grounded theory methodology on transcripts from interviews and focus groups, identify emergent themes in survivorship experiences among AYAs with cancer.

Acknowledgments