Impact of treatment and insurance on socioeconomic disparities in survival after adolescent and young adult Hodgkin lymphoma: A population-based study

Theresa Keegan, Ph.D., M.S.
Associate Professor
Department of Internal Medicine
Division of Hematology and Oncology
I have no financial relationships to disclose.

I will not discuss off label use and/or investigational use in my presentation.
Learning objectives

- Understand how survival after Hodgkin lymphoma has changed over time and by patient sociodemographic characteristics in California.

- To increase understanding of the factors underlying the observed sociodemographic disparities in survival among adolescent and young adult Hodgkin lymphoma patients.
Why study cancer in AYAs?

- AYAs (Adolescents and Young Adults) are persons 15-39 years of age
- AYAs fall between two medically well-studied populations
  - Children
  - Adults
- Understudied because not very prone to disease
- Yet, distinctive health needs
- For cancer, they have been the focus of NCI
  - Progress Review Groups in 2006 and 2013
Why study cancer in AYAs?

- ~70,000 AYAs diagnosed with cancer every year in the United States
  - Cancer incidence increasing in 20-34 years-olds

- Timing of diagnosis and treatment could have substantial effects on education, work and relationships

- Cancer is the leading cause of death in this age group after unintentional injury, homicide and suicide
Why study cancer in AYAs?

- Fewer improvements in survival relative to other age groups
  - Prior reports showing no survival improvement in more than 20 years among 25-35 year-olds
  - Recent update showing survival is not improving to the same extent in AYAs as children or older adults for a number of cancers

- Important to understand the factors underlying these survival disparities
Figure 2. Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997
Why is survival not improving in AYAs?

- **Delays in diagnosis**
  - Low suspicion of cancer
  - Lack of regular health care provider
  - Among patients, attitudes of invincibility
    - Ignore symptoms

- **Lack of medical insurance**
  - Delay in seeking care
  - Poor access to medical care for initial diagnosis and follow-up care
  - Associated with stage at diagnosis, under-treatment and mortality
Why is survival not improving in AYAs?

- Unique biological characteristics that influence response to treatment
- Lack of available clinical trials hampering efforts to develop novel therapies
- Location and specialty of treating physicians
  - Community versus cancer center
  - Pediatric versus adult protocols
  - Access to clinical trials and supportive care services
Why is survival not improving in AYAs?

- Suboptimal compliance to medications

- Mobile population
  - Difficult to find and monitor for complications and late effects

- Lack of communication with treatment providers after treatment is completed
  - Want to move on with their lives
Hodgkin lymphoma (HL)

- One of the most common cancers of adolescents and young adults (AYAs) 15 to 39 years of age

- Age-adjusted incidence rates (per 100,000), 2007-2011, SEER 18*
  - Children (<15): 0.7 (males), 0.5 (females)
  - AYAs (15-39): 3.7 (males), 3.6 (females)
  - Older adults (>39): 3.8 (males), 2.5 (females)

*SEER 18—NCI Surveillance, Epidemiology and End Results program covering 18 geographic regions in US
Hodgkin lymphoma (HL)

- 5-year relative survival, 2002-2006, SEER 18*
  - Children (<15): 96.0%
  - AYAs (15-39): 93.4%
  - Older adults (>39): 72.8%

- Annual percentage change (APC) in 5-year relative survival, 1992-2006, SEER 13*
  - Children (<15): 0.45 (p<0.001)
  - AYAs (15-39): 0.32 (ns)
  - Older adults (>39): 0.68 (p<0.05)

*SEER 18/13=NCI Surveillance, Epidemiology and End Results program covering 18 or 13 geographic regions in US
5-year relative survival of HL diagnosed in 1992-1996 (thin curve) and 2002-2006 (thick curve) by age at diagnosis, SEER13*

Hodgkin lymphoma (HL) survival

- Combined-modality regimens (radiation plus chemotherapy) have led to improvements in survival over time, but not for all patient subgroups.

- Worse HL survival observed among:
  - Young (15-44 years) blacks and Hispanics (vs NH whites)
  - Young HL patients of lower socioeconomic status (SES)


**Fig. 1** Relative survival after Hodgkin lymphoma by age (years) and neighborhood socioeconomic status (SES) group (Lower SES = quintiles 1, 2, 3; Higher SES = quintiles 4, 5), California, 1988–2006

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<th>White</th>
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<th>Black</th>
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<th>Hispanic</th>
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<th>Asian/Pacific Islander</th>
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<td>Lower SES (Q&lt;sup&gt;+&lt;/sup&gt; 1–3)</td>
<td>82.1 (1.1)</td>
<td>Lower SES (Q&lt;sup&gt;+&lt;/sup&gt; 1–3)</td>
<td>74.6 (3.1)</td>
<td>Lower SES (Q&lt;sup&gt;+&lt;/sup&gt; 1–3)</td>
<td>78.1 (1.8)</td>
<td>Lower SES (Q&lt;sup&gt;+&lt;/sup&gt; 1–3)</td>
<td>81.4 (4.6)</td>
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<td>Higher SES (Q&lt;sup&gt;+&lt;/sup&gt; 4,5)</td>
<td>88.1 (0.8)</td>
<td>Higher SES (Q&lt;sup&gt;+&lt;/sup&gt; 4,5)</td>
<td>80.4 (4.0)</td>
<td>Higher SES (Q&lt;sup&gt;+&lt;/sup&gt; 4,5)</td>
<td>79.7 (3.0)</td>
<td>Higher SES (Q&lt;sup&gt;+&lt;/sup&gt; 4,5)</td>
<td>89.0 (3.2)</td>
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</table>
Disparities may be due to variations in initial treatment and management

- Observed similar disparities for overall and HL-specific survival and the persistent difference in relative survival by neighborhood SES over time

- Blacks (52%) and Hispanics (47%) were more likely to receive chemotherapy alone (as compared with combined-modality) than non-Hispanic (38%) or Asian/Pacific Islanders (APIs) (40%)

Disparities may be due to variations in initial treatment and management

- Population-based data on AYAs with early-stage HL (1995-2010)
  - Evaluated recent trends omitting use of radiation therapy due to late effects of this therapy: cardiovascular disease and subsequent primary malignancies

- Lower utilization of radiation therapy among
  - Blacks and Hispanics
  - AYAs residing in lower SES neighborhoods

- Higher mortality among Blacks and Hispanics, and AYAs not receiving radiation
  - Omission of radiation: HR: 1.34; 95% CI: 1.07 – 1.67

Disparities may be due to variations in initial treatment and management

- National Cancer Data Base analysis among adults with early-stage HL (2003-2011)
  - Evaluated combined-modality therapy (CMT) versus chemotherapy alone
- Found use of CMT declining and lower use among
  - Younger patients
  - Blacks
- CMT was associated with better overall survival than chemotherapy alone
  - HR: 0.61; 95% CI, 0.53 to 0.70

Disparities may be due to inadequate health insurance

- Adult HL patients who were uninsured were less likely to receive CMT (Olszewski et al, 2015)

- AYAs who were uninsured, had public health insurance or resided in lower SES neighborhoods were more likely to be diagnosed with advanced-stage HL (Smith et al, 2012)

- No prior studies considered the influence of both receipt of initial CMT and insurance on sociodemographic survival disparities in AYAs with all stages of HL

Impact of Treatment and Insurance on Socioeconomic Disparities in Survival after Adolescent and Young Adult Hodgkin Lymphoma: A Population-Based Study

Theresa H.M. Keegan¹, Mindy C. DeRouen², Helen M. Parsons³, Christina A. Clarke²,⁴, Debbie Goldberg², Christopher R. Flowers⁵, and Sally L. Glaser²,⁴

Abstract

Background: Previous studies documented racial/ethnic and socioeconomic disparities in survival after Hodgkin lymphoma among adolescents and young adults (AYA), but did not consider the influence of combined-modality treatment and health insurance.

Methods: Data for 9,353 AYA patients ages 15 to 39 years when diagnosed with Hodgkin lymphoma during 1988 to 2011 were obtained from the California Cancer Registry. Using multivariate Cox proportional hazards regression, we examined the impact of sociodemographic characteristics [race/ethnicity, neighborhood socioeconomic status (SES), and health insurance], initial combined-modality treatment, and subsequent cancers on survival.

Results: Over the 24-year study period, we observed improvements in Hodgkin lymphoma-specific survival by diagnostic period and differences in survival by race/ethnicity, neighborhood SES, and health insurance for a subset of more recently diagnosed patients (2001–2011). In multivariable analyses, Hodgkin lymphoma-specific survival was worse for Blacks than Whites with early-stage [HR: 1.68; 95% confidence interval (CI): 1.14–2.49] and late-stage disease (HR: 1.68; 95% CI, 1.17–2.41) and for Hispanics than Whites with late-stage disease (HR: 1.58; 95% CI, 1.22–2.04). AYAs diagnosed with early-stage disease experienced worse survival if they also resided in lower SES neighborhoods (HR: 2.06; 95% CI, 1.59–2.68). Furthermore, more recently diagnosed AYAs with public health insurance or who were uninsured experienced worse Hodgkin lymphoma-specific survival (HR: 2.08; 95% CI, 1.52–2.84).

Conclusion: Our findings identify several subgroups of Hodgkin lymphoma patients at higher risk for Hodgkin lymphoma mortality.

Impact: Identifying and reducing barriers to recommended treatment and surveillance in these AYAs at much higher risk of mortality is essential to ameliorating these survival disparities.

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Study aims

- Determine whether previously observed racial/ethnic and socioeconomic disparities were still evident after consideration for:
  - Health insurance (from 2001 forward)
  - Combined-modality therapy (CMT)
  - Tumor characteristics
  - Demographic characteristics
  - Subsequent cancers

- Identify sociodemographic patient subgroups that have not benefited from effective treatments
Methods

- Stratified Cox proportional hazards regression evaluated impact of prognostic factors on HL-specific and overall survival
  - Hazard ratios (HR) and 95% Confidence Intervals
  - Evidence of a violation of proportional hazards assumption with stage at diagnosis, combined-modality therapy and subsequent cancers; therefore, stratified Cox proportional hazards regression models are presented

- Conducted analyses by stage at diagnosis (Ann Arbor Stage I/II vs III/IV)
  - Differences by race/ethnicity and neighborhood SES
Methods

- Included AYA patients diagnosed with classical HL in California from 1988 to 2011 (n=9,353)
  - Follow-up and cause of death information through 2012
  - Excluded patients with evidence of HIV infection or who died of AIDS

- Additional registry data: age, gender, marital status, stage, diagnosis period, B symptoms, histologic subtype, treatment at an NCI-designated hospital, urban and non-urban residence
Neighborhood Socioeconomic Status

- Census block group measures of education, poverty, income, employment, and housing
- Quintiles based on statewide distribution

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<th>Yost Socioeconomic Index Quintile</th>
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<td>5 (highest)</td>
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<td>Patients without high school diploma (age 25+ years), %</td>
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Individual versus Neighborhood Socioeconomic Status (SES)

- Individual-level measures not collected by US cancer registries

- Studies have found health effects of neighborhood SES above those of individual measures
  - Individual measures have stronger associations

- Our neighborhood SES measure incorporates aspects of education, income, occupation and cost of living, and has been used extensively in California Cancer Registry data
How could neighborhood SES influence health?

- Social environment (e.g. social support, attitudes towards health)
- Physical environment (e.g. pollution)
- Built environment (e.g. availability of health services, recreational opportunities)
A framework for studying cancer outcomes
AYA Cancer Survivors

**Predisposing Characteristics**
Patient characteristics at cancer diagnosis: age, gender, race/ethnicity, marital status, employment status, children

**Clinical characteristics:** cancer type, stage, treatment, recurrence

**Enabling Resources**
- Social support
- Health insurance
- Information and service needs met
- Socioeconomic status

**Health Practices and Concerns**
**Health behaviors:** physical activity, smoking, alcohol consumption, diet, body size

**Use of health services:** fertility preservation, services, medical care (who saw, where; how often, what discussed, routine check-ups, screening tests)

**Health concerns:** fear of recurrence

**Outcomes**
- Young adult (cancer) impact/achievements: perceived life impact (18-item checklist): Relationship impact (dating; getting married, having children; sexual functioning; body image)
- Economic impact/debt (work, financial situation, education)
- Physical symptoms/late effects: symptom inventory, comorbidities/late effects, fatigue (PedsQL), depression, sleep dysfunction
- Functioning: physical, emotional, social, and work/school functioning (PedsQL and SF12)
- General health (SF12)
- Survival/ mortality

Adapted from Anderson’s (1995) version of the Behavioral Model for Health Services Utilization. Feedback loops are recognized, but not currently depicted in this model
Results—Differences by race/ethnicity

- **Advanced stage at diagnosis**
  - Black (40%) and Hispanic (37%)
  - Non-Hispanic (NH) Whites (31%) or Asian/Pacific Islanders (APIs) (34%)

- **Treatment with chemotherapy alone**
  - Black (54%) and Hispanic (49%)
  - NH Whites (40%) or APIs (42%)

- **Public or no health insurance**
  - Blacks (35%) and Hispanics (39%)
  - NH Whites (17%) or APIs (16%)
Percentage (%) of adolescent and young adult Hodgkin lymphoma patients undergoing radiation therapy by year of diagnosis, California, 1988-2011
Figure 2.
Kaplan-Meier curve of Hodgkin lymphoma (HL)-specific survival in adolescent and young adult patients, by combined-modality therapy and stage of disease (stage I/II, stage III/IV), California, 1988–2011. The vertical axis represents survival probability; the horizontal axis represents survival time in years. Combined-modality therapy (dotted black line), radiotherapy only (solid black line), chemotherapy only (dotted gray line), no or unknown therapy (solid gray line).
Figure 2.
Kaplan-Meier curve of Hodgkin lymphoma (HL)-specific survival in adolescent and young adult patients, by combined-modality therapy and stage of disease (stage I/II, stage III/IV), California, 1988–2011. The vertical axis represents survival probability; the horizontal axis represents survival time in years. Combined-modality therapy (dotted black line), radiotherapy only (solid black line), chemotherapy only (dotted gray line), no or unknown therapy (solid gray line).
Main findings

- Regardless of stage at diagnosis, Blacks were 68% more likely to die from HL than NH whites
  - Blacks HR: 1.68; 95% CI: 1.17-2.41

- Hispanics who were diagnosed at later stages of the disease were 58% more likely to die than NH whites diagnosed at a similar stage
  - Hispanics HR: 1.58; 95% CI: 1.22 – 2.04
AYA patients who were uninsured or had public health insurance were twice as likely to die from the disease, even when their disease was diagnosed at an early stage
- HR: 2.08; 95% CI: 1.52 – 2.84

AYAs with early stage disease who resided in low SES neighborhoods were over twice as likely to die from the HL
- HR: 2.06; 95% CI: 1.59 – 2.68
Main findings

- Survival improving over-time

- Health insurance attenuated associations for neighborhood SES (up to 22%) and race/ethnicity (≤9%)
  - SES associations still evident (HR: 1.67; 95% CI: 0.97-2.86)

- Receiving initial care at an NCI-designated cancer center not associated with survival
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Stage I/II</th>
<th>Overall survival&lt;sup&gt;a&lt;/sup&gt;</th>
<th>HR (95% CI)</th>
<th>Deaths</th>
<th>HL-specific survival&lt;sup&gt;a&lt;/sup&gt;</th>
<th>HR (95% CI)</th>
<th>Deaths</th>
<th>Stage III/IV</th>
<th>Overall survival&lt;sup&gt;a&lt;/sup&gt;</th>
<th>HR (95% CI)</th>
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<th>HL-specific survival&lt;sup&gt;a&lt;/sup&gt;</th>
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<td>1988–1992</td>
<td>250</td>
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<td>2.87</td>
<td>(1.79–4.60)</td>
<td>239</td>
<td>135</td>
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<td>(1.64–3.37)</td>
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<td>(1.03–2.55)</td>
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<td>(1.18–2.39)</td>
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<td>1.28</td>
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<td>1.42</td>
<td>(0.99–2.04)</td>
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<td>1.02</td>
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<td>Black</td>
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<td>1.39 (1.04–1.86)</td>
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<td>1.68</td>
<td>(1.14–2.49)</td>
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<td>38</td>
<td>1.55</td>
<td>(1.17–2.06)</td>
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<td>1.68 (1.17–2.41)</td>
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<td>68</td>
<td>1.10</td>
<td>(0.82–1.48)</td>
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<td>106</td>
<td>1.31</td>
<td>(1.07–1.62)</td>
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<td>1.58 (1.22–2.04)</td>
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<td>Asian/Pacific Islander</td>
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<td>1.09 (0.74–1.61)</td>
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<td>1.22</td>
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<td>(0.82–1.74)</td>
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<td>1.22 (0.76–1.97)</td>
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<td>Neighborhood socioeconomic status</td>
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<td>Low (Quintiles 1–3)</td>
<td>389</td>
<td>1.77 (1.48–2.11)</td>
<td>204</td>
<td>2.06</td>
<td>(1.59–2.68)</td>
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<td>228</td>
<td>1.20</td>
<td>(1.00–1.44)</td>
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<td>228</td>
<td>1.15 (0.92–1.45)</td>
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<td>Health insurance status, limited to patients diagnosed from 2001 to 2011&lt;sup&gt;b&lt;/sup&gt; (n = 4,406)</td>
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<tr>
<td>Private/military insurance</td>
<td>78</td>
<td>Reference</td>
<td>50</td>
<td>Reference</td>
<td></td>
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<tr>
<td>Public insurance/no insurance</td>
<td>53</td>
<td>2.19 (1.49–3.21)</td>
<td>37</td>
<td>2.07</td>
<td>(1.30–3.30)</td>
<td>69</td>
<td>49</td>
<td>2.09</td>
<td>(1.46–2.99)</td>
<td>49</td>
<td>49</td>
<td>2.16 (1.41–3.32)</td>
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<tr>
<td>Unknown</td>
<td>5</td>
<td>1.05 (0.42–2.64)</td>
<td>&lt;5</td>
<td>~</td>
<td></td>
<td>6</td>
<td>5</td>
<td>1.36</td>
<td>(0.58–3.20)</td>
<td>5</td>
<td>5</td>
<td>1.63 (0.63–4.21)</td>
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</tbody>
</table>
Chemotherapy alone is associated with worse survival
- Trends in decreased use of radiation
- Blacks and Hispanics, AYAs residing in lower SES neighborhoods, and AYAs with public or no insurance were more likely to receive as initial treatment

Despite survival benefits with radiation, this therapy is associated with subsequent primary malignancies
- Higher proportion of patients who received radiation for their HL had subsequent cancer (4.9% versus 6.9%)
- Subsequent cancers are associated with worse survival
- Modern treatments with lower radiation doses may result in fewer subsequent malignancies
Our findings are consistent with those of prior studies, but limited by
- Lack of data prior to 2001
- Lack of information after initial diagnosis and treatment

In AYA cancer survivors, health insurance
- Rates have been found to decrease with time
- Lack of insurance is a barrier to receiving medical care

Even with insurance, AYA cancer survivors more likely to forgo medical care due to costs

Important to continue to monitor how health policy changes improve access to health insurance and impact outcomes
Limitations

- **Treatment**
  - Limited to initial course
  - Potential for under-ascertainment
  - Lacks details, such as dose or specific drugs/regimens

- **Lack of clinical information in the cancer registry**
  - Prognostic serum measures
  - International prognostic index
  - Health behaviors
  - Comorbidities/late effects/medical conditions

- **Large and diverse cohort that received care across all types of institutions**
  - 32% followed for $\geq$15 years; mean follow-up 11 years
  - Generalizable findings
Factors underlying social disparities in survival

- Late stage at diagnosis
- Variations in treatment
- Health insurance
- Quality of follow-up care
- Comorbidities/late effects/medical conditions
- Health behaviors
- Other patient/genetic factors
Factors underlying social disparities in survival

- Inadequate long-term follow-up in patients could result in a delay in diagnosing and treating medical conditions or late effects.

- Financial concerns, including lost wages, copayments, high deductibles, childcare and transportation costs can be burdensome and influence care.

- Higher prevalence of poor health behaviors and comorbidities in lower-SES and non-White patients can influence outcomes.
AYA Cancer Survivors

Predisposing Characteristics
Patient characteristics at cancer diagnosis: age, gender, race/ethnicity, marital status, employment status, children

Clinical characteristics: cancer type, stage, treatment, recurrence

Health Practices and Concerns
Health behaviors: physical activity, smoking, alcohol consumption, diet, body size
Use of health services: fertility preservation, services, medical care (who saw, where; how often, what discussed, routine check-ups, screening tests)
Health concerns: fear of recurrence

Enabling Resources
Social support
Health insurance
Information and service needs met
Socioeconomic status

Outcomes
Young adult (cancer) impact/achievements: perceived life impact (18-item checklist):
Relationship impact (dating; getting married, having children; sexual functioning; body image)
Economic impact/debt (work, financial situation, education)

Physical symptoms/late effects: symptom inventory, comorbidities/late effects, fatigue (PedsQL), depression, sleep dysfunction

Functioning: physical, emotional, social, and work/school functioning (PedsQL and SF12)

General health (SF12)

Survival/ mortality

Adapted from Anderson’s (1995) version of the Behavioral Model for Health Services Utilization. Feedback loops are recognized, but not currently depicted in this model.
Elevated risk of health problems AYA cancer survivors

- Many AYA cancer survivors have a lifelong elevated risk of chronic health problems as a consequence of the curative cancer therapy.

- Increased mortality among many cancer survivors, including HL survivors, related to second primary cancers and cardiovascular disease (CVD).


Fig 2. Cumulative incidence curves of cardiovascular disease events over time by cancer survivor status.

AYA HL cancer survivors at an increased risk for hospitalizations

- Danish 5-year HL survivors face persistent risks throughout life for a range of diseases
  - 87% increased risk for being hospitalized
  - Highest risk for infections, second cancers and blood system diseases (anemias, coagulation defects, hemorrhagic conditions, agranulocytosis)

- Excess risks of late morbidity resulting in hospitalization were observed among 442 5-year HL survivors (15-24 years at diagnosis) in British Columbia


Leukemia, brain cancer, HL and NHL survivors had the highest excess risk of hospitalizations, 49% of hospitalizations among all survivors.


<table>
<thead>
<tr>
<th>Cancer type</th>
<th>Ob, No.; RR (95% CI)</th>
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</thead>
<tbody>
<tr>
<td>All cancer survivors</td>
<td>53032; 1.38 (1.37-1.39)</td>
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<tr>
<td>Leukemia</td>
<td>482; 2.21 (2.02-2.42)</td>
</tr>
<tr>
<td>Brain cancer</td>
<td>2747; 1.93 (1.86-2.00)</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>2769; 1.87 (1.80-1.94)</td>
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<tr>
<td>Non-Hodgkin lymphoma</td>
<td>1521; 1.64 (1.56-1.73)</td>
</tr>
<tr>
<td>Testicular cancer</td>
<td>7286; 1.47 (1.43-1.50)</td>
</tr>
<tr>
<td>Thyroid cancer</td>
<td>1225; 1.45 (1.37-1.53)</td>
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<tr>
<td>Breast cancer</td>
<td>6006; 1.34 (1.30-1.37)</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>12904; 1.27 (1.25-1.29)</td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td>1545; 1.17 (1.12-1.23)</td>
</tr>
<tr>
<td>Malignant melanoma</td>
<td>4093; 1.11 (1.08-1.15)</td>
</tr>
</tbody>
</table>
Each year, nearly 5 of 100 HL survivors were hospitalized for a new excess disease.

Cancer control continuum

- Advances in early detection and treatment have turned a once fatal disease into a chronic condition
  - 5-year relative survival of 93.4% in AYAs with HL

- Care of those with cancer involves a circular cancer-control model
  - Post-treatment care focuses on
    - Treating lingering effects of illness
    - Control or early detection of late effects
    - Health promotion

Figure 4. Cancer Control Continuum – Revisited. (Reprinted with permission.64 Rowland. Cancer Survivorship: Rethinking the Cancer Control Continuum. Sem Oncol Nursing 2008; 24: 145-52
Subgroups of young patients at higher risk of death from HL

- Black or Hispanic AYAs
- AYAs residing in lower SES neighborhoods
- Uninsured or publicly insured

Extends previous studies by observing disparities after considering combined-modality treatment, subsequent primary cancers and health insurance

Identifying and reducing barriers to recommended treatment and surveillance in these AYAs is essential to ameliorating these survival disparities
Acknowledgements

Theresa H.M. Keegan, Mindy C. DeRouen,¹ Helen M. Parsons,³ Christina A. Clarke,¹,² Debbie Goldberg,¹ Christopher R. Flowers,⁴ Sally L. Glaser¹,²

¹ Cancer Prevention Institute of California
² Department of Health Research and Policy (Epidemiology), Stanford University School of Medicine
³ Department of Epidemiology and Biostatistics, The University of Texas Health Science Center at San Antonio
⁴ Department of Hematology and Oncology, Winship Cancer Institute, Emory University

Theresa Keegan
tkeegan@ucdavis.edu
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