Disparities & Barriers to Pediatric Cancer Survivorship Care

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METHODS OF THE TECHNICAL BRIEF

FINDINGS BY GUIDING QUESTION
**GUIDING QUESTIONS (GQ)**

- **GQ1** What are the disparities in survivorship care for pediatric survivors?
- **GQ2** What are the barriers to survivorship care for pediatric cancer survivors?
- **GQ3** What are proposed strategies for addressing those barriers?
- **GQ4** What published and unpublished studies have assessed these strategies?
- **GQ5** What are the future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?
**Methods:** Scoping Review

**Aim**
Objective description of current science, framework for assessing interventions, identification of future research needs

**Inclusion Criteria**
1. Childhood cancer survivors of all ages
2. Authors' definition or ≥ 50% of sample diagnosed prior to age 21
3. Received primary acute treatment for any cancer
4. Currently in remission
5. Currently receiving or eligible to receive survivorship care services, care plans, and/or models of follow-up care

**Protocol**
AHRQ Effective Healthcare website
Federal Register

**Data Collection**
1. Key informants
2. Grey literature
3. Published & ongoing research
### KEY INFORMANTS

#### PATIENT, CAREGIVER, & FAMILY
- Kaitlyn Ash, BS  
  Live For Today
- **Shelley Fuld Nasso, MPP**  
  National Coalition for Cancer Survivorship

#### HSR & ACCESS TO CARE
- Jennifer Tsui, PhD  
  University of Southern California
- Robin Yabroff, PhD  
  American Cancer Society

#### CLINICAL & PATIENT CARE
- Kira Bona, MD, MPH  
  Dana Farber Cancer Institute
- Eric Chow, MD, MPH  
  Fred Hutchinson Cancer Research Center
- Deborah Friedman, MD, MS  
  Vanderbilt University Medical Center
- Melissa Hudson, MD  
  St. Jude Children's Research Hospital

#### ADMINISTRATIVE & PAYER
- Jennifer Malin, MD, PhD  
  United Healthcare
Records identified through database searches
n = 6,624

Additional records identified through other sources
n = 234

Citations screened
n = 6,858

Excluded citations, not comparative study, not systematic review, or not relevant to topic
n = 4,371

Full-text articles excluded
n = 2,131
- Participants: n = 691
- Intervention: n = 439
- Comparator: n = 7
- Outcome: n = 656
- Setting: n = 6
- Study Design: n = 132
- Duplicate: n = 188
- Not English: n = 12

Full-text publications assessed for eligibility
n = 2,487

Background
n = 195

Included studies
n = 110 reported in 161 publications
GUIDING QUESTION 1

DISPARITIES

What are the disparities in survivorship care for pediatric cancer survivors?
The diagram illustrates the relationship between disparate factors (Biological Sex, Race or Ethnicity, Income, Employment) and outcomes (Survivorship Care, Health Services & Economics, Psychosocial, Biomedical) across different domains (Insurance, Underserved or Rural, Education, Other*).

- **Survivorship Care** includes utilization of services, care plans, and models of care.
- **Health Services & Economics** encompasses utilization, quality and satisfaction with care, and financial hardship, costs.
- **Psychosocial** focuses on quality of life, education, employment, and substance use.
- **Biomedical** covers late effects and morbidity, adverse events, and mortality.

The diagram also indicates the number of studies supporting each relationship: 
- ≥10 studies
- 5-9 studies
- 1-4 studies

*Other frequently includes age and year at diagnosis, age and marital status at study, diagnosis, and type of treatment received and intensity.*
26 studies investigated disparities in survivorship care for pediatric cancer survivors.
GUIDING QUESTION 2

BARRIERS

What are the barriers to survivorship care for pediatric cancer survivors who experience disparities?
This is a diagram that illustrates the relationship between barrier levels, barrier types, and outcomes by domain. The diagram shows how different factors at the patient, caregiver, and local environment levels can lead to various types of barriers, which in turn affect outcomes in different domains.

**Barrier Level**
- Patient
- Caregiver, Family, or Local Environment

**Barrier Type**
- Knowledge of need for life-long survivorship care
- Financial or employment resources
- Trust in providers or medical community
- Patient autonomy
- Cultural, language, and literacy
- Prioritization of survivorship care

**Outcomes by Domain**
- **Survivorship Care**
  - Utilization of services
  - Care plans
  - Models of care

- **Health Services & Economics**
  - Utilization
  - Quality and satisfaction with care
  - Financial hardship, costs

- **Biomedical**
  - Late effects and morbidity
  - Adverse events
  - Mortality

- **Psychosocial**
  - Quality of life
  - Education, employment
  - Substance use

The diagram uses arrows to indicate the direction of influence, with different line types representing the number of studies that support each relationship. For example, ≥10 studies, 5-9 studies, 1-4 studies.
BARRIERS

STUDIES ASSESSED BARRIERS TO SURVIVORSHIP CARE

Patient
Caregiver, family member, or community
Provider
Health system
Payer
GUIDING QUESTION 3

PROPOSED STRATEGIES

What are proposed strategies for addressing those barriers?
<table>
<thead>
<tr>
<th>Organization (Year)</th>
<th>Country</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Society of Paediatric Oncology (1996)</td>
<td>Multiple countries</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>International Society of Paediatric Oncology (2004)</td>
<td>Multiple countries</td>
<td>Meeting Summaries and Recommendations</td>
</tr>
<tr>
<td>United Kingdom Children’s Cancer Study Group: Late Effects Subcommittee (2005)</td>
<td>UK</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>UK Children’s Cancer Study Group (UKCCSG) Late Effects Group (LEG) (2006)</td>
<td>UK</td>
<td>Clinical Practice Guideline</td>
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<tr>
<td>Children’s Oncology Group Nursing Discipline (2007)</td>
<td>USA</td>
<td>Meeting Summaries and Recommendations</td>
</tr>
<tr>
<td>American Academy of Pediatrics (2009)</td>
<td>USA</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>Late Effects Taskforce of the Dutch Childhood Oncology Group (2010)</td>
<td>Netherlands</td>
<td>Clinical Practice Guideline</td>
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<td>Scottish Intercollegiate Guidelines Network (2013)</td>
<td>UK</td>
<td>Clinical Practice Guideline</td>
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<td>American Academy of Pediatrics (2014)</td>
<td>USA</td>
<td>Policy Statement</td>
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<tr>
<td>Working Group on Adolescents, Young Adults, and Transition (2017)</td>
<td>Germany</td>
<td>Meeting Summaries and Recommendations</td>
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<td>Children’s Oncology Group (2018)</td>
<td>USA</td>
<td>Clinical Practice Guideline</td>
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<tr>
<td>Cancer Leadership Council (2019)</td>
<td>USA</td>
<td>Policy Statement</td>
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<td>National Comprehensive Cancer Network (2020)</td>
<td>USA</td>
<td>Clinical Practice Guideline</td>
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<tr>
<td>International Guideline Harmonization Group (2020)</td>
<td>Multiple countries</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>Children's Cancer Cause (2020)</td>
<td>USA</td>
<td>Policy Statement</td>
</tr>
</tbody>
</table>
PROPOSED ORGANIZATIONS
ACKNOWLEDGED DISPARITIES

STRATEGIES
LIMITED INFORMATION ABOUT BARRIERS
GUIDING QUESTION 4

EVALUATED STRATEGIES

What published and unpublished studies have assessed these strategies?
Studies evaluated the effectiveness of strategies to reduce disparities and barriers to pediatric cancer survivorship care.
GUIDING QUESTION 5

FUTURE DIRECTIONS

What are future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?
Ongoing studies included directions for future research on disparities and barriers to pediatric cancer survivorship care.
**Next Steps**

**Population**
Social determinants of health
Engagement in health system

**Interventions**
Technology
Risk stratification
Individually-tailored at multiple levels

**Outcomes**
Under/over surveillance
Facilitators of desired outcomes

**Study Design**
Multi-site, longitudinal studies
Economics-based studies
Thank You!

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