Gaps and Opportunities in Cancer Control for Individuals with Intellectual and/or Developmental Disabilities

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Background & Study Purpose

• Cancer is the second leading cause of death in the United States
• Individuals with intellectual and/or developmental disabilities (IDD) have high rates of comorbid conditions which may contribute to their risk for cancer
• Cancer control is defined as programs intended to prevent cancer, find cancer earlier, and improve cancer treatment and survivorship
• Individuals with IDD experience barriers to cancer control services and limited information is known about their experiences with cancer care and survivorship
• The purpose of this scoping review was to understand what is currently known about cancer care and survivorship services for individuals with IDD

Methods

Initial Search of NCBI/PubMed, Psychinfo, Ovid, CINAHL, Embase, Scopus and Web of Science
Years 2006-2018
N=1,272

Exclusion Criteria
• Non-disability population
• Disability arising from cancer
• Cancer domains other than treatment and/or survivorship (i.e. cancer screening)
  • Genetic and molecular/cellular studies
  • Duplicate article or conference abstract

Removed
N=1,260

Full Text Review
N=12
• Indexed for methodology, country of origin, disability type, cancer diagnoses, ethical considerations & study findings
• Two researchers reviewed separately then discussed collectively to identify common themes, trends in the literature, and directions for future research

Results

<table>
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<tr>
<th>First Author (Year)</th>
<th>Methodology</th>
<th>Country of Origin</th>
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<td>Flynn (2015)</td>
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<td>Jarzine (2015)</td>
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<td>Canada</td>
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Theme One: The need to support professional and family caregivers
Theme Two: The importance of collaboration among health providers
Theme Three: Ethical approaches to discussing cancer prognoses
Theme Four: Need for policies and standards of care for individuals with IDD with cancer

Implications

• Research: Given the uniqueness of U.S. health system, more U.S. based research is necessary to identify best practices for inclusive cancer care
• Policy: A medical home model could allow for better cancer care coordination
• Practice: More standards of care and specialized training focused on the unique needs of individuals with IDD are needed

Acknowledgments

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