

**ARE RESEARCHERS ADDRESSING CANCER TREATMENT AND SURVIVORSHIP IN PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN THE U.S.? A SCOPING REVIEW**

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**ARE RESEARCHERS ADDRESSING CANCER TREATMENT AND SURVIVORSHIP AMONG PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN THE U.S.? A SCOPING REVIEW**

**Abstract**

People with intellectual and developmental disabilities (PWIDD) often encounter barriers in the health care system when seeking general and specialized medical care. Literature has shown that PWIDD experience a lack of proper screening for and prevention of cancer compared to the general population. However, less is known regarding the cancer care and survivorship of PWIDD, especially in the United States. In this review, we examine what is currently known about the primary, psychosocial, and palliative care of PWIDD diagnosed with cancer. Our analyses reveal an immediate need for improvement in caregiver support, collaboration amongst health care providers, and ethical approaches to information disclosure for this population, as well as the establishment of more reliable standards of care through additional research with PWIDD.

*Keywords:* disability, developmental, intellectual, cancers, treatment, review

## A REVIEW OF CANCER SURVIVORSHIP IN PWIDD

Despite national calls for better care for cancer survivors (Institute of Medicine, 2006), survivorship is understudied in vulnerable and underserved populations, such as people with disabilities (Maly, Liang, Liu, Griggs, & Ganz, 2017). Although recognized as a population that experiences health disparities, people with disabilities are a significantly heterogeneous group, with a variety of impairments that shape their needs and preferences and which challenge health care providers to provide culturally competent care (Butler et al., 2016). Moreover, the lumping of people with intellectual and developmental disabilities (PWIDD) together may create lacunae in identifying the special concerns of patients who require highly individualized care. While this review of the literature includes both developmental and intellectual disabilities within its scope, we made every attempt to note when research specifically focuses on one population or the other. Our multidisciplinary team, which brought together the perspectives of cancer and disability researchers, a disability practitioner, and a primary care physician, conducted this review to examine the extant research regarding cancer survivorship and PWIDD in order to assess and recommend areas for future research.

Previous literature describes the barriers to good health and health care access (Williamson, Contreras, Rodriguez, Smith, & Perkins, 2017), for adults with intellectual disabilities (ID), particularly in the areas of sexuality and reproduction (Greenwood & Wilkinson, 2013), cancer prevention and screening (Greenwood & Wilkinson, 2013; Wilkinson & Cerreto, 2008), and living with chronic disease (Flynn, Hulbert-Williams, Bramwell, & Hulbert-Williams, 2015b). Studies showed patterns of incidence of certain types of cancer in subpopulations of PWIDD, such as increased risk of leukemia and lower risk of solid tumors (other than testicular cancer) in people with Down Syndrome (Hasle, Friedman, Olsen, & Rasmussen, 2016). However, population-based research showed that the age- standardized cancer incidence among people with intellectual disabilities (including Down syndrome) was not significantly different from the general population (Sullivan, Hussain, Threlfall, & Bittles, 2004). Furthermore, PWIDD were more likely to be overweight or obese, which potentially put them at risk for cancer (Bhaumik,

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Watson, Thorp, Tyrer, & McGrother, 2008; Draheim, 2006; Reichard & Stolzle, 2011; Reichard, Stolzle, & Fox, 2011).

Cancer control is often depicted as a continuum, from primary and secondary prevention (screening), to diagnosis, treatment and survivorship, which includes end of life (Figure 1). Previous studies indicated that breast, cervical, and colorectal cancer screening rates are lower in PWIDD (Brown, Plourde, Ouellette-Kuntz, Vigod, & Cobigo, 2016; Ouellette-Kuntz, Cobigo, Balogh, Wilton, & Lunsky, 2015; Ouellette-Kuntz, Coo, Cobigo, & Wilton, 2015; Parish, Swaine, Luken, Rose, & Dababnah, 2012; Parish, Swaine, Son, & Luken, 2013a, 2013b; Tretarre et al., 2017). Additional individual and systemic barriers to the early diagnosis of cancer in PWIDD (Satge, Kempf, Dubois, Nishi, & Tredaniel, 2016), included the lack of proper communication of healthcare information among patients and caregivers (Maly et al., 2017), patient fear or anxiety (Truesdale-Kennedy, Taggart, & McIlfatrick, 2011), and provider bias (Tyler, Zyzanski, Panaite, & Council, 2010). In response to these findings, specific interventions were developed to reduce barriers and facilitate necessary cancer screening in particular for women with IDD (Swaine, Parish, Luken, Son, & Dickens, 2014).

Less research exists about the cancer treatment and survivorship needs of PWIDD. Researchers have noted the lack of accessible cancer information for PWIDD, and found that these patients had a desire for information, for emotional support, and for facilitated discussion about their experiences with cancer (Collins, McClimens, Mekonnen, & Wyld, 2014); (Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006). As the general population of people treated for cancer grows – estimated to be more than 43.8 million worldwide (International Agency for Research on Cancer, 2018)– it is imperative to prepare for and address the specific needs of subpopulations that may require extra support (Miller et al., 2016).

According to the Institute of Medicine (2006), good survivorship care requires efforts toward cancer prevention (e.g. lifestyle changes), surveillance (e.g. monitoring for spread or recurrence), management of the effects of cancer and its treatment, and coordination between

specialists and primary care. Research with the general population of cancer survivors outlines social and behavioral barriers to survivorship care in the U.S., due to a fragmented health care delivery system, lack of patient and provider awareness of the issues specific to cancer survivorship, and poor patient-provider communication (Institute of Medicine 2005). Moreover, international concern regarding the methods for ensuring quality of care during survivorship (Grunfeld, 2006) saw countries like the UK implementing survivorship models in national health systems (Oeffinger et al., 2014). However, less is known regarding social and behavioral barriers to cancer survivorship care among vulnerable populations, including PWIDD. Using the Institute of Medicine's (2006) definition of survivorship as beginning at the point of diagnosis, the purpose of this scoping review is to explore the extant social and behavioral research of cancer survivorship, beginning with cancer treatment for PWIDD. The fairly large body of literature addressing health promotion/prevention and surveillance can be informative for providers in managing the care of PWIDD in survivorship; however, here, we include research regarding health promotion/cancer prevention and surveillance only if it expressly addresses those concerns in the survivor population.

### **Methods**

To assess what is currently known about social and behavioral issues in cancer treatment and survivorship amongst PWIDD, we employed a three-stage method for a scoping review of the literature. Scoping reviews are beneficial for mapping out the depth and breadth of methodologically diverse literature on a topic (Levac, Colquhoun, & O'Brien, 2010). The first two stages, outlined in Figure 2, involved identifying appropriate literature, whereas the third stage required a review and analysis of the relevant findings (Levac et al., 2010). We began with a preliminary search of the literature, which was followed by a secondary review and abstraction of data, and a final assessment of the articles that were identified as relevant (Levac et al., 2010).

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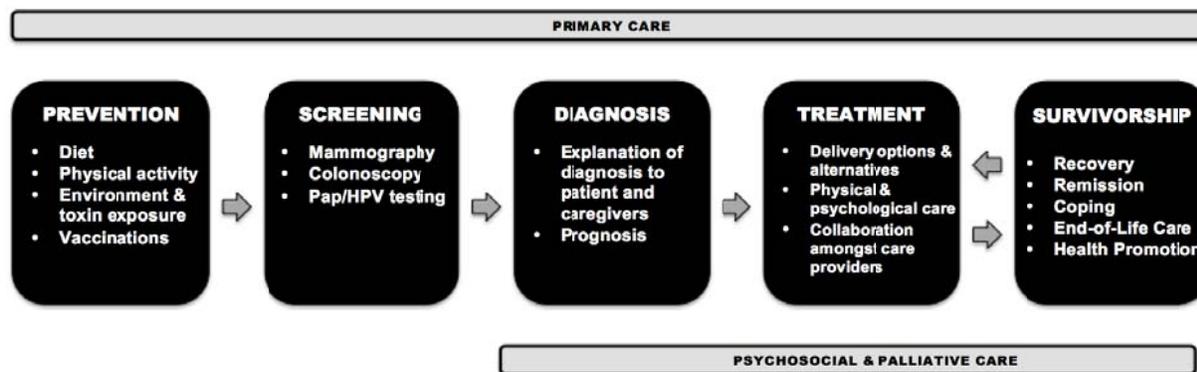
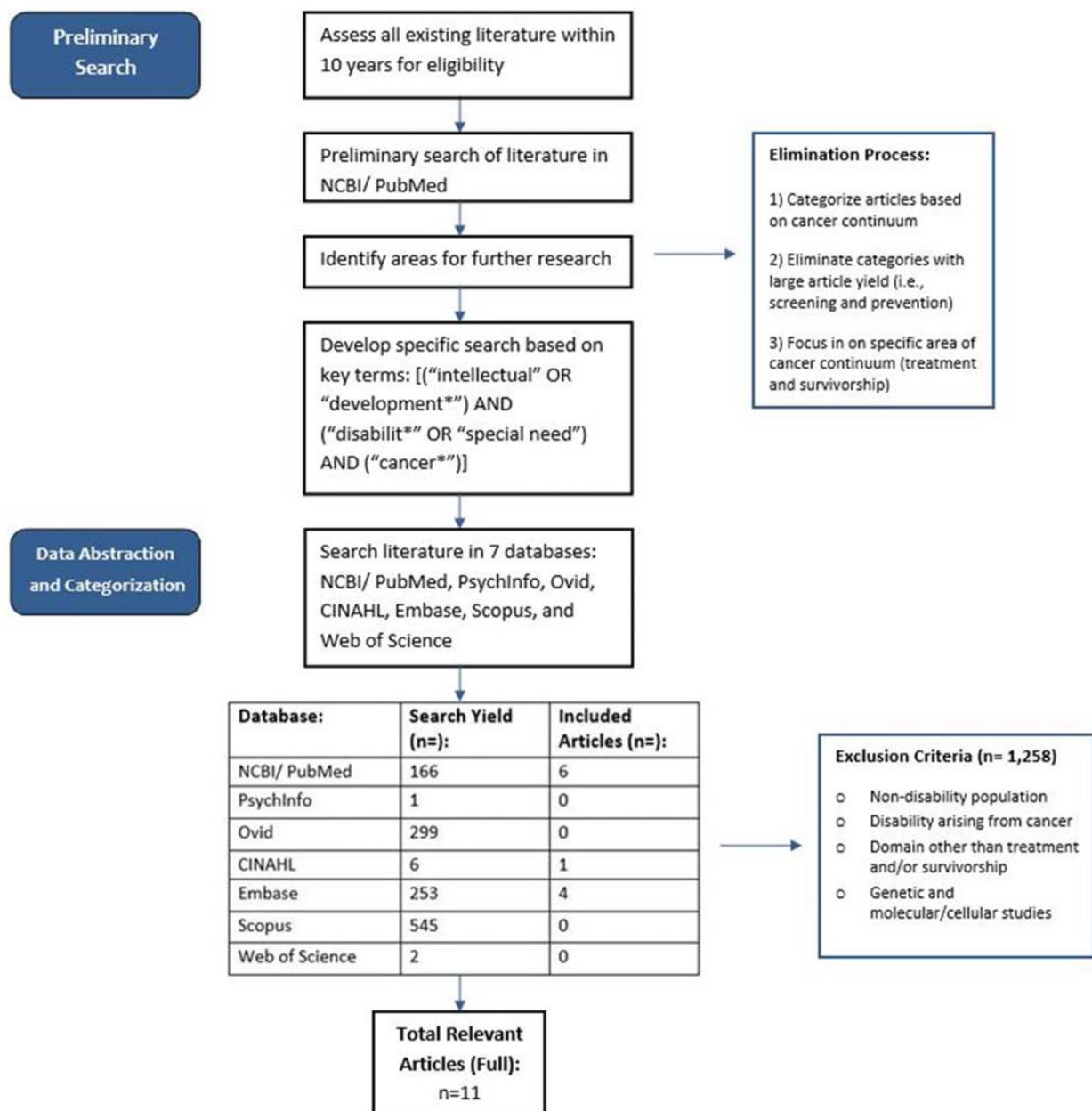


Figure 1: Cancer Continuum

Diagram of major steps in cancer care process. Adapted from (National Cancer Institute, 2017).

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**Figure 2: Outline of Review Process**

Preliminary search produced 11 full articles; one additional full article was produced upon further review of references cited (n=12).

### Stage 1: Scoping Search of the Literature

We began the review process by establishing the scope of the research domain (Arksey & O'Malley, 2005). Specifically, the initial search examined all existing literature within the last 10 years (2006 – 2016) with a broad focus on all parts of cancer continuum. Since that initial search, the team has added articles that were published in the interim or that we identified in a bibliography scan of the initial sample of articles. The categories included medical risk factors, prevention and screening, diagnosis, treatment, and survivorship.

We created our initial search of the NCBI/ PubMed, PsychInfo, Ovid, CINAHL, Embase, Scopus, and Web of Science databases based on specific parameters and key terms (Fig. 1), which were revised in various combinations to yield the most relevant results. Specifically, we first conducted a Boolean search [(“intellectual” OR “development\*”) AND (“disabilit\*” OR “special need”) AND (“cancer\*”)] in the NCBI database. The results of this search were used to determine the distribution of current literature that addresses aspects of the cancer continuum (Arksey & O'Malley, 2005).

## **Stage 2: Identifying Areas for Further Research**

The results of the initial NCBI search were then categorized based on each part of the cancer continuum (Fig. 2), with an additional category of “medical risk factors”, as much of the literature investigated specific molecular and cellular predispositions to cancer in people with developmental disabilities. The goal of this approach was to identify areas in the existing literature that could benefit from further research.

We found a large body of literature (hundreds of articles) on the screening and prevention side of cancer care for PWIDD. However, once cancer treatment and survivorship became our focus, these articles were eliminated, leaving the study team to adapt the initial search terms to better suit the focus of the scoping review (Levac et al., 2010). We adapted our

initial search strategy to yield a final Boolean search combination of (“intellectual” OR “development”) AND (“disabilit\*” OR “special need”) AND (“cancer\*” and “treat\*” or “therap\*”), which was applied in the seven aforementioned databases using a title and abstract search. This revised search specifically focused on the treatment and survivorship side of this continuum, which involves primary treatment, psychosocial, and palliative care. Prevention and surveillance, which are components of survivorship, are not explicitly addressed in this review.

The refined search yielded 1,272 articles, which was narrowed down to 11 final relevant articles and 3 conference abstracts based on our exclusion criteria (Fig. 1). Further review of references identified one additional article, for a total of 12 relevant articles. It is important to note that this search commonly yielded research exploring the experience of disability manifesting from cancer treatment. However, our intent was to explore cancer survivorship issues experiences by those living with a disability prior to their cancer diagnosis. Furthermore, this search produced articles that focused on cellular medical treatments of cancer, which were also eliminated as they did not align with the research question we sought to address (Levac et al., 2010). While the initial intention was to focus on cancer treatment and survivorship amongst PWIDD in the U.S., the research revealed studies primarily based in other countries. Given the paucity of research in this arena, our research team included all studies regardless of geographic setting.

### **Stage 3: Full Text Review**

We went on to abstract data from the 12 identified articles and 3 conference abstracts into a spreadsheet, which included information such as study methodology, country of origin, disability and cancer diagnoses, inclusion and exclusion criteria, ethical considerations, and study findings. Two researchers reviewed each article separately to collect the data (Levac et al., 2010). These same two researchers then compared their data abstraction results to identify, discuss and resolve any inconsistencies in abstraction. Once abstraction was finalized, the

authors identified common themes in study findings, determined trends in the literature, and highlighted directions for future research, as described in the Results and Discussion sections.

## Results

A detailed review of the relevant literature revealed four major themes: 1) the need to support professional and lay-caregivers of PWIDD diagnosed with cancer; 2) the importance of collaboration among health-care providers; 3) ethical approaches to discussing cancer prognoses with PWIDD; and 4) the need for policies and standards of care for PWIDD with cancer. Generally, the articles highlighted that patients' experience and quality of treatment was dependent on not only the people directly responsible for their healthcare, but also those responsible for higher levels of policy-making that determine methods of practice. Table 1 shows the publications by type, method, and country where the research took place. Of the 12 selected articles, 5 (41.7%) were qualitative, 2 (6.7%) were quantitative; 3 (25.0%) used mixed methods, and 2 (16.7%) were descriptive (e.g. medical case studies). Analysis of distribution of articles by countries of origin (Fig. 3) revealed that 8 (66.7%) studies took place in the United Kingdom (UK), 1 (8.3%) in the United States (U.S), and 3 (25.0%) in other countries (France, Canada, and Australia).

### **Theme 1: The Need to Support Medical Professionals, Paid Caregivers, and Family Caregivers**

Much of the research represented in this review examined the experiences of caregivers for PWIDD undergoing cancer care, acknowledging the interpersonal relationships that are very common for PWIDD, who may rely on paid and informal support people for daily activities. Particularly, research identified medical professionals, paid support personnel, and unpaid family members as the primary stakeholders. Though psychosocial cancer care is traditionally

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directed towards the patient, the literature reported a great need for emotional support and education for professional and lay care providers as well.

<b>Article Title:</b>	<b>Authors:</b>	<b>Type:</b>	<b>Method:</b>	<b>Country of Origin:</b>
“Breast cancer information and support needs for women with intellectual disabilities: a scoping study”	K. Collins, A. McClimens, S. Mekonnen, L. Wyld	Journal article	Qualitative	UK
“Caring for cancer patients with an intellectual disability: Attitudes and care perceptions of UK oncology nurses”	S. Flynn, L. Hulbert-Williams, R. Bramwell, D. Stevens-Gill, N. Hulbert-Williams	Journal article	Quantitative	UK
"You don't know what's wrong with you": an exploration of cancer-related experiences in people with an intellectual disability”	S. Flynn, N. Hulbert-Williams, L. Hulbert-Williams, R. Bramwell	Journal article	Qualitative	UK
“Commentary on ‘Overcoming challenges in diagnosing and treating cancers in people with intellectual disability: a case analysis’”	J. Foster, B. Marks	Journal article	Mixed	UK
“Supporting people with intellectual disability in the cancer journey: The ‘Living with cancer’ communication pack”	T. Gilbert, T. Wilkinson, S. Crudgington	Journal article	Mixed	UK
“Pre-Morbid Developmental Vulnerabilities in Children With Newly Diagnosed Acute Lymphoblastic Leukemia (ALL)”	L. Janzen, D. David, D. Walker, J. Hitzler, S. Zupanec, H. Jones, B. Spiegler	Journal article	Mixed	Canada
“Overcoming challenges in diagnosing and treating cancers in people with intellectual disability: a case analysis”	R. Kiani, A. Vahabzadeh, E. Hepplewhite, M. Abbas, T. Finnermore, S. Bhaumik, D. Satge	Journal article	Descriptive	UK
Reproductive Cancer Treatment	S. Parish, E. Son, R.	Journal	Quantitative	US

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Hospitalizations of U.S. Women with Intellectual and Developmental Disabilities. Intellectual and Developmental Disabilities	Powell, L. Igdalsky	Article		
“Adenocarcinoma of the Right Breast in a Man with Intellectual Disability”	D. Satge, B. Leduc, F. Raffi, E. Roux	Journal article	Descriptive	France
“Hospitalisation for cancer and co-morbidities among people with learning disability in Australia”	S. Sullivan, Rafat Hussain	Journal article	Qualitative	Australia
“Developing Guidelines for Disclosure or Non-Disclosure of Bad News around Life-Limiting Illness and Death to People with Intellectual Disabilities”	I. Tuffrey-Wijne, N. Giatras, G. Butler, A. Cresswell, P. Manners, J. Bernal	Journal article	Qualitative	UK
“Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: Findings from an ethnographic study”	I. Tuffrey-Wijne, J. Bernal, S. Hollins	Journal article	Qualitative	UK

**Medical Professionals and Paid Caregivers.** Medical professionals include nurses, physicians, medical technicians, and other personnel essential to the treatment process in a clinical setting. The literature showed that often times, it is not considered how the perceptions, concerns, and education of these individuals can affect the treatment process. For example, a 2015 UK-based study found that oncology nurses were generally less comfortable treating patients with intellectual disability (ID) than those without it, primarily due to a lack of prior experience (Flynn et al. 2015a). Flynn and colleagues reported that these nurses had a negative perception about treating patients with ID, as it was viewed as a more stressful and difficult process. As a result, some patients with ID may experience a lower quality of treatment from medical professionals who experience unease due to unfamiliarity with patient needs and background. Similarly, paid caregivers, such as in-home support personnel, may have a background in palliative care, but still be unfamiliar with the strategies for working with PWIDD

unless they have received specialized education and training. This may lead to a compromised level of care for PWIDD.

**Family Caregivers.** The aforementioned study also pointed towards a need to research the “complex emotional impact” on family caregivers that accompanies the cancer care of PWIDD (Flynn et al., 2015a). A heavy emotional burden was observed in family members who were directly responsible for decisions regarding treatment. Research has urged the medical field to move towards providing counseling and support services for families, as these necessary services appear to be scarce (Sullivan & Hussain, 2008). For instance, Flynn and colleagues concluded that family carers were often more emotionally affected during the treatment process than the patients themselves (Flynn et al., 2015a). The researchers concluded this is likely due to the responsibility of serving as a communication liaison between the medical personnel and the patient. Particularly, it was found that oncology nurses relied mostly on family carers to communicate medical information to the patient, as they were uncomfortable doing it themselves (Flynn et al., 2015a). As concluded in an ethnographic study by Tuffrey-Wijne and colleagues, more support is needed for family members, as the process of disclosure regarding diagnosis, prognosis, and treatment processes could be highly stressful for them (Tuffrey-Wijne, Bernal, & Hollins, 2010).

A greater support system for medical professionals, paid caregivers and family caregivers is necessary to promote positive perceptions and confidence in the cancer care of PWIDD. For medical personnel and paid caregivers, support may include greater familiarization with the needs of PWIDD prior to treatment, while family carers may benefit from a shared responsibility with medical professionals in communicating sensitive information to the patient.

## **Theme 2: The Importance of Collaboration Among Healthcare Providers**

PWIDD and cancer patients often have a complex network of healthcare providers, each addressing a particular aspect of their condition and needs. For instance, a cancer patient might have a primary care physician, an oncologist, a psychiatrist, and a palliative care specialist as

part of their treatment team, while PWIDD may have their own set of specialists to address disability-related issues. An Australian study emphasized the elevated risk for PWIDD (called “learning disability” in Australia and the UK) to develop chronic illnesses, such as cancers and affective disorders, particularly among people with Down syndrome. Broadly, it was found that co-morbidities significantly complicated treatment processes and consequently, could result in worse treatment outcomes (Sullivan & Hussain, 2008).

Several reports, such as a grounded theory study by Flynn et al. regarding cancer experiences in this population, highlighted the need for a high degree of care coordination in order to ensure the best standard of care for PWIDD with cancer (2015b). Articles advanced the importance of communication between primary and specialty (oncology) healthcare. A case analysis by Kiani and colleagues (2014) which discussed adenocarcinoma treatment in a man with severe ID found that he was not given a proper cancer diagnosis until after death, even though his x-rays revealed an abnormality in his right lung and despite several episodes of pneumonia. The authors concluded that this man’s care was “fragmented”, and claimed that the delay in his diagnosis and consequently in his treatment could have been prevented with more collaboration between members of his health care team. As concluded by Foster and Marks (2014) in their commentary of Kiani’s case analysis, there is a need for general practitioners to perform annual health checks for PWIDD as they would with any other patient, so that critical diagnoses are not missed.

Furthermore, the patient experience of healthcare can be improved if all members of the oncology care team have an understanding of a patient’s disability. In her 2015 grounded theory study, Flynn and colleagues concluded that raising oncology teams’ awareness of IDD diagnosis would improve the overall health-care experience for patients and family carers (Flynn et al., 2015a). In particular, the authors argued that the psychological adjustment to a cancer diagnosis is similar in PWIDD as it is to the general population, but the incidence of

psychological and supportive care challenges are much greater due to lack of accessible psychosocial information and support.

### **Theme 3: Ethical Approaches to Disclosing Cancer Information**

The process of disclosure of sensitive medical information (i.e., regarding diagnosis, prognosis, and details about treatment procedures) can be difficult for both medical personnel and family carers. Research has advocated for streamlined and structured disclosure in order for patients and proxies to be able to prepare for medical costs and make informed treatment decisions (Sullivan & Hussain, 2008). Unfortunately, one study found that PWIDD are often excluded from treatment discussions, which can lead to anxiety about and disengagement from treatment (Flynn, Hulbert-Williams, Hulbert-Williams, & Bramwell, 2016). The authors pinpointed the need for encouraging self-determination in PWIDD in order to increase their engagement in medical decision-making (Flynn et al., 2016). Additionally, it was shown that a greater amount of patient engagement could be achieved if patients were aided in understanding medical concepts and procedures (Flynn et al., 2015b).

One article reported on the results of a study conducted to evaluate the dissemination, acceptability, and usefulness of a tool, the “Living with Cancer” communication pack, developed to educate PWIDD and their caregivers (Gilbert, Wilkinson, & Crudgington, 2007). This tool aims to help PWIDD through the cancer journey by addressing their specific communication needs, using effective approaches such as sets of symbols and pictures that relate to health promotion and the cancer journey. Specifically, topics relevant to health promotion included “healthy eating”, “exercise”, and “cervical screening”, while those relating to the cancer journey included “what is cancer”, “chemotherapy” and “palliative care” (Gilbert et al., 2007). Findings from focus groups, telephone interviews, and questionnaires of caregivers and PWIDD demonstrated that the information resources could be used by practitioners to give them confidence in working with PWIDD and by patients to help them develop a language for talking about their bodies and emotions. Furthermore, the design of this tool was considered accessible and relevant (Gilbert

et al., 2007), being useful across a range of communication abilities and enabling patients to express their choices and feelings about their health.

Tuffrey-Wijne and colleagues (2013) observed that while intellectual disability professionals and medical professionals are generally in favor of disclosure to patients, family carers tend to be against disclosure. Flynn and colleagues (2016) reported that family carers' perspective stems from a desire to protect their family member from the reality of their diagnosis. In research with PWIDD, family carers, medical healthcare professionals (i.e., nurses and physicians) and IDD specialists, Tuffrey-Wijne and colleagues found that family carers' reasons for nondisclosure included the desire to prevent patient distress, a limited scope of patient understanding, and difficulty for the person disclosing the information. On the other hand, medical and IDD professionals were more likely to be in favor of disclosure to the patients, citing their belief in the patient's right to be informed, the need for patient involvement, and the benefit to patients' coping process (Tuffrey-Wijne et al., 2013). While family carers and medical personnel were shown to have opposing views on disclosure, Tuffrey-Wijne and colleagues' study revealed that PWIDD had a wide range of viewpoints, and those who were informed about their condition were highly resilient.

Due to the large range of understanding and viewpoints in PWIDD, Tuffrey-Wijne and collaborators argued for the disclosure process to be highly patient-centric and individualized. For example, a study investigating the breast cancer support needs of women with intellectual disabilities identified a need for "reasonable adjustments" during the care process to properly accommodate the treatment needs of a patient (Collins et al., 2014). A PWIDD may require collaboration with their primary care physician (or other professional who understands their IDD diagnosis/ impairment) and/or educational provisions that help guide them through the cancer care journey in a way that promotes inclusion. Therefore, it was concluded that the question that care providers should ask is not "if" information should be disclosed, but "what" information is best for the patient to know and "when" it should be disclosed. Tuffrey-Wijne and colleagues

(2013) argued that this approach allows for an ethical, patient-centric, and structured disclosure process.

#### **Theme 4: Policies & Practice**

The struggles of health-care providers and family carers point towards a need for better practice guidelines, driven by policy at multiple levels. A 2014 paper regarding the breast cancer support needs of women with IDD found that stakeholders identified a need for “leadership, guidance, and protocols” and a clear knowledge of who is responsible for the care of this subset of women (Collins et al., 2014). Additionally, the semi-structured interviews of stakeholders in this study led researchers to conclude that a lack of practice guidelines may lead to late diagnosis, “suboptimal” treatment and management of the patient’s condition, and lower survival rates (Collins et al., 2014).

Two articles highlighted the dangers of “diagnostic overshadowing” in PWIDD, whether it was cancer overshadowing disability-related impairment or vice versa. An illustration is the previously discussed case analysis of a man with right-side lung adenocarcinoma and severe intellectual disability, in which it was revealed that he did not receive a diagnosis of cancer until after his death (Kiani et al., 2014). Janzen and colleagues’ study of prior developmental vulnerabilities in children with recently diagnosed acute lymphoblastic leukemia (ALL) points to potential risks of excluding PWIDD from studies of the neurocognitive effects of ALL therapies. This group found that 23% of research participants screened positive with significant differences from the typically-developing group. This screening was especially important because the children with an ALL diagnosis and a pre-morbid developmental vulnerability (DV) were found to be more susceptible to the neurotoxic effects of cancer treatment. Importantly, the researchers in this study concluded that not only is it possible to screen newly diagnosed ALL patients for prior DV, but that it should be regularly done after diagnosis (Janzen et al., 2015).

Researchers examined patterns of cancer hospitalization amongst PWIDD, offering insight into the cancer burden in this population. A U.S.-based study determining the prevalence

of reproductive cancer hospitalizations in women with intellectual disability found that women with IDD were hospitalized at significantly younger ages with longer mean hospital stays than women without IDD. Furthermore, women with IDD were more likely to have public health insurance coverage and live in zip codes with a lower median income (Parish, Son, Powell, & Igdalsky, 2018). Data analyzed in this study was taken across various demographics and sourced from the 2010 Healthcare Cost and Utilization Project. While the authors noted the limitation of examining data by discharge rather than individual patient, it was concluded that there are important health delivery implications in these findings (e.g. length of hospital stay) and further research might examine both inpatient and outpatient data along with cancer outcomes (Parish et al., 2018).

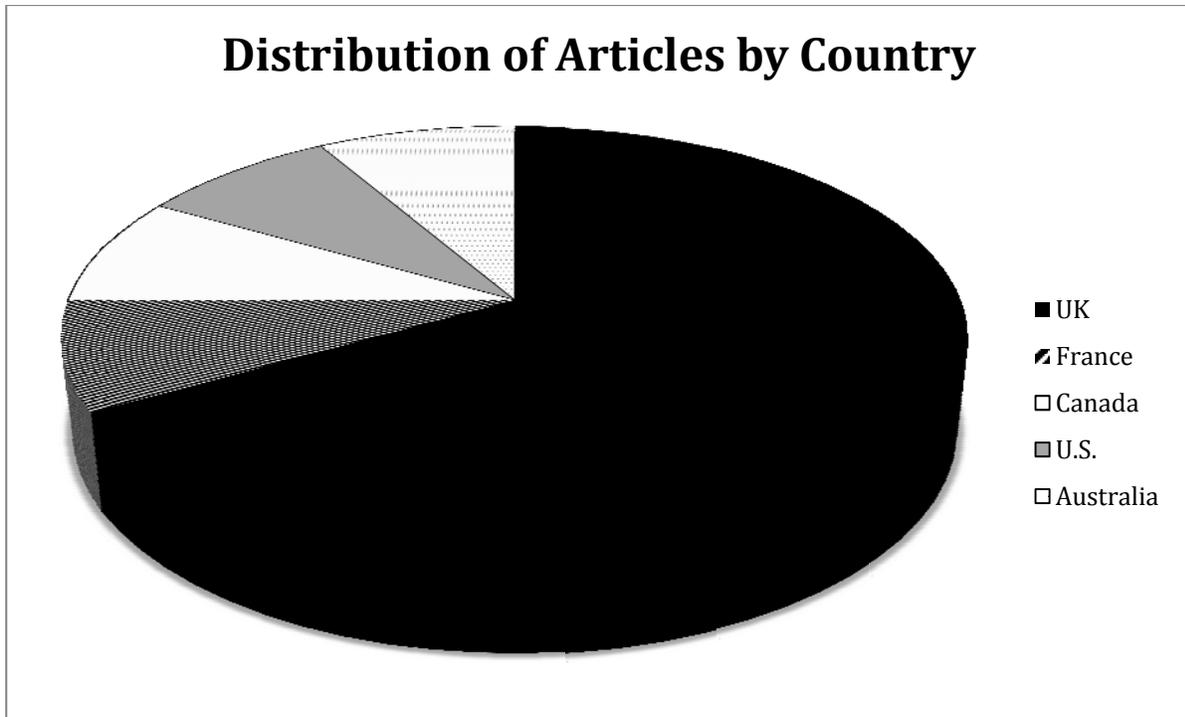
### **Discussion**

Our review notes several areas in need of further research, including gaps that have been identified for the general population of cancer survivors. In the U.S., survivorship research has expanded over the past decade and a half in response to the growing population of survivors, which is expected to grow to 18 million by 2022 (De Moor et al, 2013). Several key findings in the Institute of Medicine's call to improve survivorship care for the general population in the U.S. (IOM, 2005) presaged the findings of this literature review focused on PWIDD. Specifically, the IOM report found distinct challenges to ensuring the coordination of multidisciplinary specialist care in the United States' fragmented health care system, the need for provider education about survivors' health care needs, and barriers to effective physician-patient communication regarding survivors' concerns. In the more than a decade since the IOM report was published, researchers have documented continued challenges to effective survivorship care; many newer research findings are relevant to consider in articulating a research agenda that will facilitate tailored cancer survivorship care for PWIDD. In particular, primary care providers in the U.S report a need for greater cancer knowledge and

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skills and improved processes for managing cancer survivors (O'Malley, Davis, Crabtree, & Hudson, 2017). While researchers note the potential for primary care's integration into survivorship care, they also call for adequate description and testing of health care delivery models in varied primary care contexts and in consideration of the populations served (Nekhlyudov, O'Malley, & Hudson, 2017). Involving PWIDD in research examining the effectiveness of primary care-focused survivorship care would offer important insights into individual, interpersonal, and systemic approaches to accessible survivorship care.

As U.S.-based researchers, we note the need for additional cancer-related research in the U.S. context, as it relates to care coordination for PWIDD, cancer care decision-making among PWIDD and their families, and the need for professional training in providing cancer care for PWIDD. When discussing health-care for PWIDD, it is important to note that policy and practice are likely to differ across countries. For example, the term "intellectual disability" in the United States is referred to as "learning disability" in the United Kingdom. Each country has its own set of characteristics to define intellectual and developmental disabilities, which influences the practices employed for treatment, the standard of care offered, and the general perceptions towards research in the area. As shown in Figure 3, the majority (83.3%) of relevant studies came from the UK or other countries. In contrast, only one relevant article was identified from Canada and the U.S, respectively.



**Figure 3: Pie chart diagram of full literature by country of origin.**

Research from the UK was the most prevalent (8 articles, 66.7%), followed by an even distribution across France, Canada, Australia, and the U.S. (1 article each, 8.3% each)

These proportions illustrate the geographical distribution of cancer research related to PWIDD and raise the question of policy and practice differences between these countries that may be contributing to a lack of U.S.-based research in this area. For instance, healthcare systems in place for PWIDD in the U.S. differ greatly from those in the UK, which operates on a single-payer system and a shared electronic medical system (Bolnick & Hon, 2002). In contrast, the U.S. healthcare system can be highly fragmented, which makes information sharing and collaboration among healthcare providers difficult. The Americans with Disabilities Act (Morin, 1990) intended to reduce access barriers to all aspects of public life for individuals with disabilities, including access to health care. However, this federal policy has yet to truly accomplish in full its stated goal, likely due to oversight limitations across all sectors of public

life. In contrast, the United Kingdom's Department of Health (2001) produced the white paper *Valuing People: A New Strategy for Learning Disability* in which specific guidance was provided regarding health care access including cancer for PWIDD across the lifespan. Additionally, the United Kingdom's National Service Frameworks included specific information regarding the needs of PWIDD in their National Cancer Plan.

Core healthcare professional groups engaged in cancer survivorship care are nurses and family or general practitioners, and there are practice differences in education and training between the United Kingdom and the United States. The national accrediting body for all nursing professionals in the United Kingdom, the Nursing and Midwifery Council (2017), offers as one of its four core specialty areas specific certification for learning disabilities in nursing. In the United States, nurses can self-select to specialize through a non-for-profit nursing specialty organization, the Developmental Disabilities Nurses Association (2017), but there is nothing currently endorsed by the U.S. government. In the U.S., there is still a lack of training in disabilities for general medical practitioners (Jain, 2006), whereas in the UK, the Royal College of General Practitioners curriculum (2013) includes specific training on the care of PWIDD. Additionally, the UK's National Health Services and the Palliative Care for People with Learning Disabilities Network (2017) have produced guidelines for best practices in palliative care for PWIDD. Clearly there are contrasts in policy and practice between the UK and the U.S., which could influence the research productivity in this field and also the need for particular types of research across the world. Understanding gaps in professional knowledge regarding disability and developing and testing curricula to address these gaps may improve patient care and cancer outcomes.

Our review has observed that coordination of care is essential to provide the best standard of treatment to PWIDD. Particularly, it is important for all members of the oncology healthcare team to fully understand their patient's disability diagnosis before proceeding with treatment and disclosure practices. As these practices can be stressful, it is necessary to have

support systems (i.e., disability education services and disclosure guidelines) in place for both lay and professional caregivers. For family carers, this would ideally reduce the stress of disclosure, while medical personnel would feel more at ease with administering treatment to PWIDD. Coordination of cancer care has been identified as a challenge for the general population of patients (Hewitt, Greenfield, & Stovall, 2005), but a growing corpus of research is focusing on improving communication (Vermeir et al., 2015) and coordination (LaGrandeur, Armin, Howe, & Ali-Akbarian, 2018), which may effectively guide multidisciplinary teams to improve patient outcomes, including those of people with disabilities.

Analysis of common disclosure practices has revealed that while healthcare professionals are willing and ready to disclose medical information to PWIDD, family carers are less inclined towards disclosure with the intention of “protecting” their family member with IDD. However, research by Tuffrey-Wijne and colleagues has demonstrated that full or partial disclosure is not only beneficial to PWIDD, but is necessary as regular practice. Determining the correct amount of disclosure is based on the individual and his/her needs. With the correct disclosure practices and collaboration of the patient’s healthcare team, supporting PWIDD in decision-making during the cancer care journey is quite possible. However, one must also understand that disclosure practices should be tailored to the needs of the patient (Tuffrey-Wijne et al., 2013). There is a need to fill the gap in understanding how to tailor communications to patients with IDD and their families in order to support their decision-making, taking into consideration health literacy and communication preferences. In particular, existing approaches for discussing “difficult topics” in cancer care (e.g. palliative care) may be adapted for use with PWIDD (Wittenberg, Reb & Kanter 2018). Additionally, research that examines the dynamics of decision-making among PWIDD and their caregivers is warranted.

Furthermore, an issue in healthcare that is seldom addressed is the bias toward people with a disability (Foster and Marks (2014); Kiani et al., 2014; Tyler, Zyzanski, Panaite, & Council, 2010). Bias may affect the way that non-IDD medical personnel view and prescribe

treatment, as well as the way that policy makers consider research needs. This bias often stems from a lack of education about the disability community and can lead to a poorer standard of health care for PWIDD. Assessing this prejudice and addressing it with evidence-based education is the first step towards a more holistic, full, and ethical treatment of PWIDD's healthcare needs.

### **Limitations**

Epidemiological, health services research, and psychosocial research regarding cancer treatment and survivorship of PWIDD is an area of emerging science, particularly in the United States, and there is a need to understand the evidence. As our primary goal was to understand the state of the science in the United States, our keywords reflected terminology common in the past 10 years in the United States, e.g. intellectual and developmental disability. We did not use search terms that are common in other international context, such as "learning disability," although most of the articles covered in this review are based on original research outside of the U.S. However, it is possible that our search approach inadvertently missed some international resources because we used terminology more common in the U.S. context.

### **Conclusion**

This review clearly articulates a need for more research, particularly in the United States, about the cancer treatment and survivorship needs of PWIDD, and for aligning this research agenda with that of the general population of cancer survivors. Best practices and models of survivorship care identified through research with the general population of survivors should inform research with cancer survivors with IDD. While research conducted in the United Kingdom, Canada, or other countries can be instructive for patients with IDD, their families, and practitioners, U.S. professional education, standards of care, and care coordination differs from countries with single-payer health care systems. Moreover, with the increase in self-determination for PWIDD in the U.S. in recent decades, there seems to be a readiness for self-advocates and their allies to collaborate with researchers to examine the optimal methods for

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conveying cancer information and disclosing diagnoses and prognoses. Finally, U.S.-based research might also test the effectiveness of existing programs, such as medical homes for PWIDD, in providing education and support for oncology staff who have limited experience providing health care for PWIDD.

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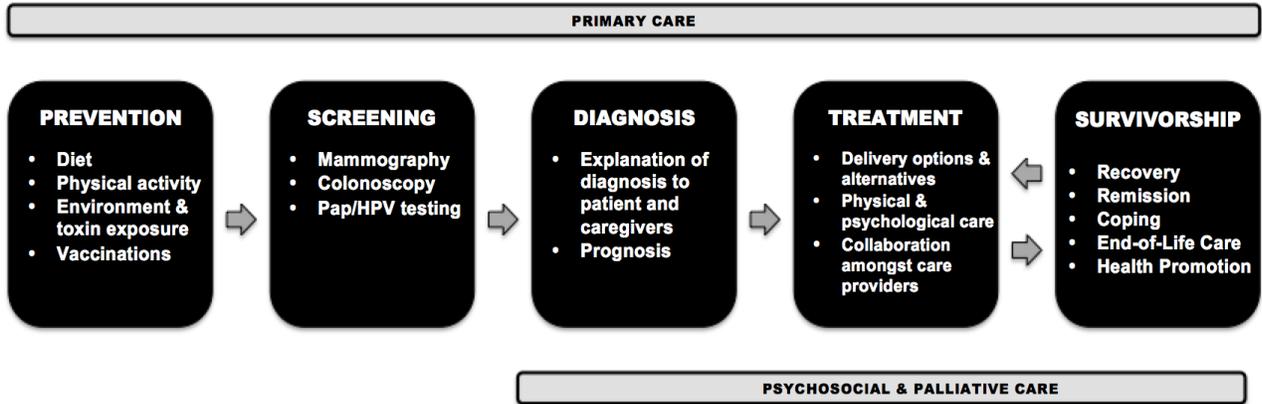
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**Preliminary Search**

Assess all existing literature within 10 years for eligibility

Preliminary search of literature in NCBI/ PubMed

Identify areas for further research

Develop specific search based on key terms: [{"intellectual" OR "development\*"}] AND [{"disabilit\*" OR "special need"}] AND [{"cancer\*"}]

**Elimination Process:**

- 1) Categorize articles based on cancer continuum
- 2) Eliminate categories with large article yield (i.e., screening and prevention)
- 3) Focus in on specific area of cancer continuum (treatment and survivorship)

**Data Abstraction and Categorization**

Search literature in 7 databases: NCBI/ PubMed, PsychInfo, Ovid, CINAHL, Embase, Scopus, and Web of Science

Database:	Search Yield (n=):	Included Articles (n=):
NCBI/ PubMed	166	6
PsychInfo	1	0
Ovid	299	0
CINAHL	6	2
Embase	253	6
Scopus	545	0
Web of Science	2	0

**Exclusion Criteria (n= 1,258)**

- o Non-disability population
- o Disability arising from cancer
- o Domain other than treatment and/or survivorship
- o Genetic and molecular/cellular studies

**Total Relevant Articles (Full):**  
n=12

## Distribution of Articles by Country

