

COMMENT

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# Breaking barriers: a commentary on research gaps in cancer and depression among individuals with intellectual disabilities

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## Abstract

The European Commission's Strategy for the Rights of Persons with Disabilities 2021–2030 aims to ensure equal opportunities and rights for all individuals, including those with intellectual disabilities. People with intellectual disabilities are often underrepresented in cancer prevention and screening policies, leading to disparities in health outcomes and early mortality. The intersection of intellectual disability, cancer, and depression represents an underexplored area in healthcare research. Individuals with intellectual disability diagnosed with both cancer and depression face compounded challenges impacting their quality of life, proper access to medical care, and treatment outcomes. To address these gaps in the systems globally, a focused effort is indispensable to understand their unique needs and better tailor care strategies for this target group. Therefore, this commentary outlines the challenges in researching individuals with intellectual disabilities who have a dual diagnosis of cancer and depression. Challenges include providing informed consent, ethical researcher–participant relationships, and maintaining confidentiality and autonomy. Strategies for improvement include creating accessible procedures, raising awareness, and involving individuals with intellectual disabilities in research ethics committees.

**Keywords** Intellectual disabilities, Cancer prevention, Research inclusion, Diagnostic overshadowing, Depression comorbidity, Health disparities

## Background

In March, the European Commission (2021) adopted the Strategy for the Rights of Persons with Disabilities for 2021–2030, aiming to ensure that all persons with disabilities in Europe, regardless of their sex, racial or ethnic origin, religion or belief, and age or sexual orientation,

enjoy human rights and equal opportunities [1]. However, people with intellectual disabilities are often underrepresented in general cancer prevention and screening policies across Europe, leading to disparities in healthcare outcomes and early deaths [2], thus preventing them from enjoying the same rights to accessible and appropriate healthcare. This situation is intensified when mental disorders such as depression are comorbid with chronic physical diseases, resulting in severe health consequences [3].

This commentary outlines the challenges with conducting research involving individuals with intellectual disabilities who have a dual diagnosis of cancer and depression. These challenges include enforcing informed consent procedures; creating ethical

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researcher–participant relationships; balancing risk-benefit ratios; and ensuring confidentiality, beneficence, justice, and participants' autonomy. This commentary will raise awareness of these issues, contribute to the ongoing debate on this sensitive subject, and provide strategies for improvement.

### **People with intellectual disabilities in medical research**

People with intellectual disabilities value and desire involvement in research as participants and researchers [4]. However, despite being frequent beneficiaries of healthcare services [5], they are routinely excluded from clinical trials and medical, public health, and epidemiological research [5–7]. For example, McDonald [8] conducted an exploratory research multimethod, qualitative approach. Overall, findings suggest that adults with intellectual and developmental disabilities value research.

Although research participation can benefit this population, their caregivers, and their families, few countries have guidelines that directly address the issue [6]. Exclusion often depends on the subjective views of the ethical review boards. A systematic review of 2710 trials indicated a lack of clarity in exclusion criteria: “In 96% the exclusion criteria were judged as ‘relative.’ Implicit exclusion criteria were present in 1205 trials (44.5%)” ([7] p. 1). Different measurement criteria were used to exclude people with intellectual disabilities. For example, McDonald ([8], p. 805) found that the measures of cognitive functioning such as the Mini-Mental Status Examination [9] were used to exclude participants often with no rationale provided.

Individuals with intellectual disabilities experience some of the highest rates of exclusion from research, especially when their disabilities are combined with depression. According to DeCormier Plosky et al. ([10], p.1427), “83% of depression-related studies included at least one exclusion for cognitive disability compared with 28% of studies for lung cancer and only 6% for diabetes”. Therefore, including people with disabilities in depression-related research is crucial as they are at high risk ([11], p. 1010). Camanni et al. [7] found that of the 2710 trials, behavioral or psychiatric disorders were the most frequently excluded (61.4%). Research integrity and underrepresentation makes research data limited or incorrect in terms of generalizability: “Not explicitly making efforts to include people with disabilities potentially skews research findings toward more ‘healthy patient populations” [5] p. 2138).

Excluding people with intellectual disabilities from studies has been identified in previous literature as a known and widespread issue in research and public health [12], which may result in the further misrepresentation of the general population, as a correlation of

disability is often observed with other factors such as poverty and unemployment [13]. Thus, balancing the pros and cons of selecting a homogeneous sample (where it is perhaps easier to detect effects but more difficult to enroll subjects, providing less generalizable results) versus a heterogeneous sample, where it is easier to enroll subjects and provides more generalizable results [14] is crucial.

### **Cancer in people with intellectual disabilities**

Despite advancements in healthcare accessibility and the substantial representation of people with intellectual disabilities in cancer prevention policies [2], they still face disparities in accessing adequate screening services, preventive measures, and treatment. According to St. John et al. [12], individuals with intellectual disabilities are particularly vulnerable to inequalities in healthcare access. This group also exhibits a considerably higher risk of premature mortality [15], with cancer, the leading cause of death (22.4% of all deaths) and being up to 1.5 times more likely as the cause of death, than the general population [16].

The two main problems here include the following: (1) people with intellectual disabilities are often underrepresented in cancer prevention and screening policies and (2) diagnostic overshadowing, which is a negative bias impacting a clinician's judgment regarding co-occurring disorders in individuals with intellectual disabilities and/or other mental illness ([17], p. 938). Notably, the increasing prevalence of cancer among disabled individuals, especially those with intellectual disabilities, long went unnoticed owing to their exclusion from research: “people with intellectual disabilities may be at an increased risk of developing cancer but more likely to present for medical treatment at a later stage when cancer has spread” ([18], p. 1).

The barriers contributing to the underrepresentation of this population include inadequate healthcare infrastructure, limited transportation and financial resources, and inadequate communication skills owing to limited health literacy and insufficient support for alternative communication methods. An inability to communicate directly impacts inequities in cancer treatment and outcomes in this group [19]. Smith et al. [20] reported a high prevalence of communication difficulties with professionals and unfamiliar persons at the rate of almost 58% in a study cohort. Impaired communicative competence in three language functions (receptive, expressive, and pragmatic) leads to a direct risk of exclusion and prevents subjects from being active interlocutors [21]. Failure to transfer information between individuals with intellectual disabilities and healthcare providers [22], a lack of educational preparedness (expressed in low levels of awareness and knowledge related to intellectual

disabilities) among healthcare professionals [23], and low levels of feeling prepared to provide care to this group of patients [24] can be identified as substantial contributors to this inequity. Khanlou et al. [25] reported a widespread inability to provide person-centered care, which in turn can cause disparities in the reception of cancer-related care.

Integrating individuals with intellectual disabilities into standard cancer and depression care requires thoughtful adjustments to ensure equitable treatment. Research emphasizes the necessity of tailoring therapies to accommodate the unique biopsychosocial needs of this population. A scoping review [26] highlighted various reasonable adjustments made for individuals with intellectual disabilities in healthcare. These included preparatory visits, extended time for medical procedures, modifications in appointment schedules, and communication accommodations to meet specific needs effectively. Corroborating the previous findings, another study [27] explores strategies for addressing the challenges faced by this population in receiving appropriate cancer and depression care. It also emphasizes the need for tailored approaches that account for the complexity of intellectual disabilities and associated psychosocial factors, aiming to improve care access, treatment efficacy, and overall well-being.

A further study [28] explored how person-centered planning (PCP)—a structured approach that focuses on the preferences and needs of individuals—can improve community participation and inclusion for adults with intellectual disabilities. It underscores the value of involving caregivers, disability support workers, and communities in the planning and delivery of services. The findings advocate for training disability support providers to actively contribute to healthcare plans, thereby ensuring that individuals can access reasonably adjusted care in various settings, including healthcare and the broader community.

Diagnostic overshadowing is a misattribution of symptoms of an undiagnosed illness to an already diagnosed comorbidity, which was first explored in patients with comorbid cognitive deficits [29] and leads to compromised patient care and contributes to increased cancer-related mortality experienced by people with intellectual disabilities [30]. In a recent literature review, the reported antecedents and consequences of diagnostic overshadowing included patients' worsening condition, a decreased likelihood to seek treatment, and death. Recognizing this issue is essential for improving patient-provider relationships and preventing the unnecessary loss of life [30]. Interpersonal stigma can be found in the attitudes and knowledge of healthcare providers toward patients with intellectual disabilities, which on an intrapersonal level impacts patients' opinions about themselves [31].

This negatively affects early detection and discourages patients with intellectual disabilities from seeking healthcare [32]. Among the causes contributing to diagnostic overshadowing, the literature reveals "fear, avoidance, lack of education, lack of confidence, and lack of clinical assessment, including symptom recognition and negative unconscious bias" ([32], p. 1363), which contribute to inadequate communication with healthcare professionals [33]. This ultimately leads to unmet healthcare needs, few cancer screenings, a lack of prevention measures, and high mortality rates.

### **Cancer and depression in people with intellectual disabilities**

Depression has been recognized as a comorbidity of cancer rather than a risk factor of cancer. Recently, the links between depression and cancer have been more widely researched [34]. In a retrospective cohort study involving 235,404 participants, the results demonstrated an increased risk of 10–39% of people with depression developing certain types of cancer [35]. A bidirectional relationship is observed between individuals with major depressive disorder who have an increased risk of cancer and cancer sufferers who develop depressive symptoms owing to the trauma of the disease [36].

When a dual diagnosis occurs, such as the comorbidity of cancer and a psychiatric disorder, people are often under-diagnosed and poorly treated [37]. Disparities in healthcare services provided to people with severe mental illness have been documented in preventive services in general, including cancer prevention and screening. For example, fewer participants with severe mental illness received effective treatment for cancer than people without, resulting in a considerably low survival rate [38]. Nonetheless, only 37% of European countries specifically allocate budget for psycho-oncological support. Moreover, mental health is not considered a priority in most Eastern European countries, with psychological distress stigmatized or underestimated [39]. Individuals requiring higher levels of support are frequently excluded from research [40]. Excluding this population from clinical research without proper justification is discriminatory, challenges various national and international regulations and research guidelines. Furthermore, it limits the generalization of studies [10].

Many with depression and intellectual disabilities may not meet the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) [41] or the Diagnostic Manual–Intellectual Disability (DM–ID) [42] owing to limitations in self-reporting their symptoms. Given that self-reporting often relies on verbal and/or linguistic abilities [43], researchers may encounter difficulties in obtaining self-reports from individuals who struggle to communicate their symptoms. For example,

fatigue is one of the most common secondary effects in cancer therapy and depressive disorders [44]. This can be a particular challenge for the intellectually disabled population, as limited verbal skills may aggravate these confounding factors [45]. Depression is a broad spectrum, making diagnoses even more challenging [36]. One recent paper showed the influence of enrollment by those other than participants or researchers, namely, clinicians, family, and paid carers [46]. Owing to the high dependency on these caregivers, recruitment for trials was determined by considerations surrounding logistics and personal consequences [46]. Depending on the stage of cancer and severity of depression, individuals with intellectual disabilities may also lack interest in participating in research [47].

When individuals with pre-existing intellectual disabilities develop cancer, the interplay between the disability, cancer, and depression therefore results in diverse treatment experiences, further influenced by other demographic factors. For individuals with intellectual disabilities, pharmacological treatment for psychiatric disorders is similar to that of the general population once a diagnosis is made. However, extra caution is needed to prevent medication interactions, incorrect dosages, and exacerbation of comorbid conditions. Additionally, people with both psychiatric disorders and intellectual disabilities may benefit from extra multidisciplinary support to ensure comprehensive care [48].

Individuals with dual-diagnosis disorders are not homogeneous; the combinations of disorders, their severity, and individual treatment needs vary. In the context of cancer and depression, a pressing need is observed to bridge gaps caused by stigma and communication issues and enhance the connections between oncology and psychiatry to develop targeted psycho-oncology programs tailored to this vulnerable population.

### **Strategies for improvement**

**Disparities in cancer and depression care for individuals with intellectual disabilities are not just inequities—they represent systemic discrimination that demands urgent attention and accountability within healthcare and research.**

Health research needs to be for everyone and is a crucial approach to addressing health disparities, particularly among underrepresented populations [49]. However, health research continues to exclude people with intellectual disabilities [50].

Although the challenges associated with including persons with intellectual disabilities in cancer and depression research have persisted for years, strategies are present that could be adopted to overcome them aimed at reducing disparities in cancer care and mental health support.

1. The use of accessible procedures, methods, language, tools, and spaces in the process of recruitment, conducting research, and research dissemination.

Researchers must ensure that research procedures, tools, and materials are suitable for individuals with intellectual disabilities and align with their abilities [51]. This includes incorporating 'reasonable adjustments' to mainstream care delivery [26], such as refining the administration of therapies to accommodate the specific nature of intellectual disabilities and the well-documented biopsychosocial contexts of this population. Recruitment efforts should not only provide accessible information about the research opportunity, its importance, benefits, and potential risks – employing plain language and assistance from caregivers when necessary – but also involve the planning roles of disability support. The inclusion of trained and educated disability support staff in treatment and research planning is vital to enable individuals with intellectual disabilities to access and participate in reasonably adjusted care. Building community partnerships remains crucial [12]. As individuals with intellectual disabilities are often connected with service providers and associations, researchers should collaborate with these organizations in recruitment while also applying standard hospital quality and safety measures to address inequitable care.

Informed consent should be obtained through formats that are accessible for participants, avoiding excessive details or technical information [12]. Special attention should be paid to individuals who lack the capacity to consent. In such cases, obtaining consent from a responsible relative or a legally authorized representative or guardian should be facilitated [52] and researchers need to ensure that this respects the participant's preferences and values [53].

Various inventive techniques have emerged that could be applied to involve participants with cognitive impairments and limited communication skills in the research process itself. In addition to using plain language, these methodologies encompass strategies that incorporate photographs, videos, and other visual data. Although there is an increasing interest in image-based visual methodologies in social research [54], this is still uncommon in medical studies, in which persons with intellectual disabilities are often regarded as unable to participate [7]. Visual approaches (with the use of picture cards, photo-story vignettes, videos, photovoice, etc.), as opposed to text-based or traditional speech-based approaches (without adjustments), have the potential to include these participants [55–57]. Finally, when disseminating the research results, accessible formats—for example, easy-to-read leaflets, videos, or social media posts—are also recommended [12].

2. Addressing the knowledge gap and raising awareness among researchers and research ethics committees.

As some researchers may lack confidence in effectively engaging and communicating with individuals with intellectual disabilities, addressing gaps in their understanding in this area is imperative [12]. A recent study [58] suggests that training programs and awareness workshops should also be organized for the members of ethics committees to protect the rights of research participants, especially in confidentiality issues. The aim of such training could include raising awareness of the potential disparities associated with intellectual functioning and power imbalances between those who conduct and those who participate in research [52] and ways of making research more accessible [12] and safe for vulnerable populations.

3. Involving persons with intellectual disabilities in research ethics committees.

Individuals with intellectual disabilities or their advocates should be involved in research ethics committees. Ensuring inclusive membership on ethics committees, comprising multidisciplinary teams with expertise in oncology and mental health, lay members from the community [59], and individuals with intellectual disabilities could help safeguard human rights and the wellbeing of all research subjects. The need for recruiting members of these committees from diverse groups—such as those from ethnic minority backgrounds or people with disabilities—has been emphasized for years [60, 61]. Yet, to our knowledge, no record exists of persons with intellectual disabilities being on such committees.

These strategies clearly require additional time and money in researching with people with intellectual disabilities [46]. Nonetheless, these challenges are outweighed by the benefits [57].

- 4- Inclusive health research.

The inclusion of individuals with intellectual disabilities in research has often been discouraged due to concerns about their vulnerability, cognitive limitations, and potential for harm [62].

Challenges include assessing their competence, ensuring understanding of research risks and benefits, and the ethical complexities of relying on surrogate decision-makers, especially in non-therapeutic research or invasive procedures. These factors have reinforced the prevailing assumption that the risks of including people with intellectual disabilities may outweigh the benefits, leading to their exclusion from many studies [63].

However, this exclusionary approach is increasingly being questioned, driven by evolving legislation in several European jurisdictions that prioritize the rights and

agency of individuals with disabilities. Notably, frameworks such as the United Nations Convention on the Rights of Persons with Disabilities [64] advocate for their active involvement in decisions that affect them, including participation in research. This shift underscores a growing recognition of the importance of inclusive research practices and the need to balance protection with empowerment.

## Conclusions

People with intellectual disabilities experience high rates of cancer and depression. However, the awareness of the risk factors and symptoms of comorbid cancer and depression is low among these individuals, their caregivers, and even healthcare professionals [65, 66]. Health equity depends on the inclusion of diverse groups in research samples. Nonetheless, intellectual disability is one of the main causes of the exclusion of persons from clinical trials, thereby creating a gap in representation [7]. Therefore, enhancing the accessibility of research on cancer and depression to persons with intellectual disabilities and to educate healthcare professionals about these issues is imperative.

## Acknowledgements

N/A.

## Author contributions

Contribution to the manuscript: LC: Writing – original draft, Writing – review & editing. LC, RV, OK, KC.

## Funding

None.

## Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate

None.

### Consent for publication

None.

### Competing interests

The authors declare no competing interests.

Received: 21 October 2024 / Accepted: 23 December 2024

Published online: 06 January 2025

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