

Identifying the deficits in cancer care for people with intellectual disabilities

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At every stage of the cancer continuum, people with intellectual disabilities are disadvantaged, leading to inequitable cancer deaths.¹ Globally, 1%–3% of people are estimated to have intellectual disabilities characterised by significant impairments in both intellectual and functional ability. Improving cancer care for people with intellectual disabilities is urgent, from understanding aetiology and prevention, to detection, diagnosis, and treatment, to address this major injustice.

The evidence base is severely limited in understanding cancer in people with intellectual disabilities, including the prevalence of cancer among people with intellectual disabilities.² Tumour growth propensities of some (genetic) intellectual disabilities syndromes could increase the risk of developing certain types of cancer. Furthermore, the entire population of people with intellectual disabilities are at increased risk of developing and dying from colorectal cancer (standardised mortality ratio 2.4 (95% CI 1.3 to 3.8)),³ which is more common in this population due to obesity, sedentary lifestyles and higher levels of constipation. People with Down's syndrome specifically are at elevated risk for leukaemia and testis carcinomas, while risk for other solid tumours seem lower.⁴ Differences in age structure complicate interpretation of cancer risks and comparisons with the general population; life expectancy of people with intellectual disabilities is generally lower, but ageing and age-related diseases have earlier onset.⁵

The differences in cancer risk and earlier onset of disease potentially impacts on the type of cancers to screen for and the age of screening onset, as the balance of benefits and harms of screening may differ for people with intellectual disabilities. Uptake of cancer screening is strikingly lower among people with intellectual disabilities compared with the general population⁶ and strategies to improve access are urgently required. But

most cancers present symptomatically which is particularly challenging for people with intellectual disabilities. A range of patient, healthcare and multimorbidity factors put people with intellectual disabilities at risk of diagnostic delays and limit opportunities for early interventions. Recognition of cancer symptoms may be overshadowed by the manifestation of intellectual disabilities traits. For example, an inability to express pain, due to communication barriers, and limited disease insight and body awareness can result in behavioural changes for people with intellectual disabilities, for example, rubbing stomach. In a recent study of cancer in deceased adults with intellectual disabilities, over one-third of cancers were diagnosed via emergency presentations and almost a half were at advanced stages when diagnosed.⁷ In a population-based cross-sectional study in Canada, people with intellectual disabilities were more likely to have stage IV breast and colorectal cancer at diagnosis compared with the general population.⁸

People with intellectual disabilities receive less cancer-related care compared with the general population⁹ with cancer treatments tending to be less intensive, including dose reduction and omission of chemotherapy or radiotherapy, despite limited evidence to support this approach.¹⁰ In particular, little is known about the effectiveness of treatment in specific genetic intellectual disabilities subgroups. Scientific knowledge about cancer treatment tolerance is mostly limited to case reports on patients with syndromic intellectual disabilities; evidence has not yet been included in treatment guidelines which puts people with intellectual disabilities at risk of unwanted treatment variation. Shared decision-making and legal capacity for cancer treatment with patients with intellectual disabilities can be challenging, potentially leading to suboptimal treatment decisions. Health professionals and family members may be hesitant to offer or accept cancer treatment for people with intellectual disabilities. They may have concerns



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about the safety or tolerance of the treatment, or the additional psychological and behavioural needs of the person with intellectual disabilities despite the potential for reasonable adjustments to be made to support patients with cancer with intellectual disabilities.¹¹ Reasonable adjustments should be tailored to the needs of the individual and could include, for example, a doula for adults with intellectual disabilities and cancer who could support and ease the treatment process.¹²

Some guidelines on palliative and end-of-life care of patients with intellectual disabilities are available, however, none are included in cancer treatment guidelines. A recent review also found no published work on cancer survivorship in people with intellectual disabilities.¹

There are significant gaps in the evidence base on care for people with intellectual disabilities across the cancer continuum globally. Much of the existing research is based on old data when people with intellectual disabilities had much shorter life expectancies and data are often incomplete making conclusions challenging. These gaps limit the ability of clinicians and policy-makers to reduce the cancer burden in people with intellectual disabilities and contribute to discrimination and ableism within oncology care.¹³ Research is urgently required from understanding the epidemiology to best treatment and survivorship if we are to address this injustice in cancer care impacting our most vulnerable in society.

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