

- **Name of the study:** People with Intellectual and Developmental Disabilities Diagnosed with Cancer: The Experience of Illness and Coping with Cancer
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Abstract

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In recent decades, the life expectancy of people with intellectual disabilities (ID) has increased substantially, leading to a higher prevalence of chronic illnesses, including cancer. However, studies have indicated that individuals with ID experience significant disparities in cancer diagnosis, treatment, and access to medical services, and their perspectives are often absent from the clinical and research discourse. Few studies have explored how people with ID perceive and cope with cancer. Thus, this study examined the illness experience and coping processes of people with ID and cancer by eliciting their voices. The study employed a qualitative methodology and included 18 in-depth, semistructured interviews with men and women aged 30–78 diagnosed with mild to moderate ID and different types of cancer. Data were analyzed using reflexive thematic analysis. Findings indicated that most participants had only limited knowledge of their illness and in some cases, they had not received clear explanations about the nature of their cancer or treatment. Information was often conveyed by guardians or residential staff members, resulting in confusion, passivity, and a sense of lack of control. Fear, primarily of death, pain, and medical procedures, was the dominant emotional response, yet emotional communication with healthcare professionals was scarce. Some participants concealed their illness, especially from peers and other residents. Nonetheless, participants also described receiving support from family, and residential caregivers. In conclusion, there is an urgent need to provide accessible medical information and facilitate communication by healthcare providers for people with ID. Tailored emotional support and professional training for healthcare and social services staff members are also essential. Furthermore, the findings call for the

development of comprehensive policies to ensure equity in healthcare, reduce gaps in diagnosis and care, and promote the participation of people with ID in medical decision-making processes that affect their lives.

Keywords

intellectual disabilities, cancer, medical information, illness experience, coping, support, concealment

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