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Cancer experiences in individuals with an intellectual disability: Results from a grounded theory study

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BACKGROUND: Increasing numbers of people with an intellectual disability (ID) are diagnosed with cancer, partly due to increased life expectancy. However, there is a paucity of research exploring their cancer experiences. Receiving a cancer diagnosis is distressing; this may be exacerbated by additional challenges faced by people with an ID.

AIMS: To explore the cancer-related experiences of individuals with an ID. A multiple stakeholder perspective was adopted, collecting data from patients, family members and their caregivers. The purpose was to: (a) identify unmet needs in this population, and (b) to generate theory and encourage further research.

METHODS: Using objectivist grounded theory methods, 6 index participants (individuals with an ID and cancer) and 12 linked participants (4 family members; 1 Medical Oncologist; 5 ID Professionals; 2 Social Workers) took part in semi-structured interviews. Interviews were transcribed verbatim and analysed concurrently to data collection.

RESULTS: All index participants perceived a delayed diagnosis, and had limited understanding of diagnostic and treatment procedures. This lack of explanation increased anxiety levels and led to disengagement. Index participants, and some caregivers, were disenfranchised from their own experiences, often yielding to others (i.e. professional carers) and devaluing their own role.

CONCLUSIONS: The vulnerability of people with an ID who are diagnosed with cancer was clear. Although emergent themes are often reported in research with non-ID cancer samples, there seems a higher incidence of difficulty in almost every aspect of diagnosis and treatment for this group. Future research should aim to reduce the disparity experienced by this population.