

## **“You don’t know what’s wrong with you”: An exploration of the cancer-related experiences of people with an intellectual disability**

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Increasing numbers of people with an intellectual disability (ID) are being diagnosed with life-altering illnesses, including cancer; this is in part due to increasing life expectancy. It is widely accepted that receiving a cancer diagnosis is psychologically distressing; it is probable that such distress may be exacerbated by the additional challenges faced by people with ID, for instance: interpersonal communication skills, personal care, reading and knowledge. However, there is a paucity of research exploring the cancer experiences of this population. Without a firm understanding of such experiences, cancer care for individuals with ID may not sufficiently meet the needs of these individuals, potentially leading to a disparity of health experience compared with patients without ID.

The research presented explores the cancer-related experiences of six individuals with ID, and those who supported them (4 family members, 5 healthcare professionals and 3 social care professionals); with the aim of identifying unmet needs in this population, generating theory and encouraging further research. Interviews were transcribed verbatim and analysed; in accordance with grounded theory methodology, analysis took place concurrently with data collection.

Individuals with an ID were often excluded from conversations about their care, and treatment related decisions; with caregivers being relied upon to facilitate communication and understanding. Where healthcare professionals possessed good patient-centred skills, and additional support was offered, meaningful engagement in their cancer experience was more likely to be achieved. Whilst emergent concepts were similar to those previously reported in general psycho-oncology literature, the incidence and degree of difficulty appeared to be greater. These findings warrant further exploration, with a requirement for interventional research which develops methods to reduce the disparity of experience, improving the overall experience for the patient, caregivers and healthcare professionals alike.