

## PAPER

# “You don't know what's wrong with you”: an exploration of cancer-related experiences in people with an intellectual disability

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**Abstract**

**Objective** Few empirical studies have explored cancer-related experiences of people with an intellectual disability (ID), despite rising cancer incidence in this population. The present research aims to better understand the experiences of this population from multiple perspectives, generating theory and further research questions.

**Methods** Six people with ID and cancer, alongside 12 participants from their supportive network (including family and social and health care professionals), were interviewed; transcripts were analyzed using grounded theory.

**Results** People with ID were often overlooked within cancer consultations and excluded from conversations about their care and treatment-related decisions. Caregivers (family and paid) were relied upon to facilitate communication and understanding and supplement health care professional knowledge. Caregivers' attempts to protect the patient from distress harmed communication further; our interviewees suggest that increased involvement and empowerment mediated cancer-related distress. Where health care professionals possessed good patient-centered skills, and additional support was offered, people with ID were more likely to engage meaningfully in their cancer-related experience.

**Conclusions** Interestingly, emergent concepts were consistent with general psycho-oncology literature; however, incidence and severity of difficulty was substantially greater in this sample. This disparity warrants further exploration, with a need for intervention research to develop effective ways of supporting health care professionals in enhancing patient-centered skills with this population. In the clinical setting, patient involvement in health care decisions (despite problems associated with comorbidity) is imperative to optimize engagement.

**KEYWORDS**

cancer, diversity, equality, intellectual disabilities, oncology, psychosocial experiences

## 1 | BACKGROUND

There are upwards of 1 million people with an intellectual disability (ID) in the UK<sup>1</sup>; a recent meta-analysis estimated global prevalence at 10.37/1000 population.<sup>2</sup> An ID is characterized by impairments in *intellectual functioning* (typically an IQ of below 70) and *adaptive functioning* including skills required for independent daily living, with onset during the developmental period.<sup>3</sup>

Increasing numbers of people with ID are being diagnosed with cancer; it has been suggested that this is in part due to increasing life

expectancy.<sup>4–6</sup> Proportionally, cancer deaths are reported to be lower in people with ID than in the general population (12–18% vs 26%)<sup>7</sup> although missed diagnoses may explain this discrepancy.<sup>8</sup>

People with an ID face barriers when accessing health care including limited organization knowledge about ID, inhibitive staff perceptions, and problems with communication.<sup>9</sup> Moreover, people with an ID are likely to have poor symptom awareness and may not seek medical assistance for potential health concerns<sup>10</sup>; implications of such delays in symptom identification and diagnosis for both physical and psychological outcomes are evident.<sup>11</sup>

A recent systematic review exploring the psychosocial experiences of people with ID and chronic illness<sup>12</sup> found that, principally, there are difficulties in communicating with care teams and understanding the illness, leading to feelings of uncertainty, confusion, and distress. In the context of the wider psychosocial oncology literature, few studies were identified focussing on the first-hand psychosocial experiences of people with ID who receive a cancer diagnosis.<sup>8,13</sup>

Considering the paucity of research within this specific population, the current study aims to present a detailed account of the cancer-related experiences of people with ID and to generate a grounded theory with relevance to both research and practice.

## 2 | METHOD

### 2.1 | Ethics

The study was approved by a University Departmental Ethics Committee and the North Wales (Central and East) Research Ethics Committee.

### 2.2 | Participants and recruitment

Our sample included data from multiple participant groups; some distinction is thus necessary. Throughout this paper, we use the term *patients* for people with ID who have been diagnosed with cancer. Family members or ID/social-care professionals will be referred to as *caregivers*, and *health care professionals* refer to oncology professionals. Whilst we realize these are not universally applicable definitions, they are intended to aid brevity.

Patients were identified by coordinators in oncology and ID settings using the following inclusion/exclusion criteria: (1) be over 18 years of age, (2) have ID and cancer diagnoses, (3) have undergone some active cancer treatment, and (4) have capacity to give informed consent, following reasonable adjustments. We recruited for 13 months during which time patients (and primary caregivers, if

appropriate) were introduced to the study during routine appointments. Those who were interested in receiving more information were sent a pack including accessibly written information. After reading this, patients contacted the research team to arrange an initial interview.

Nine people, all with a mild ID (IQ = 55-70), were invited to participate; six consented to be interviewed. Of those who did not consent, two had a progressive illness and decided not to participate, a third did not respond to the invitation. Patients nominated caregivers and health care professionals to be interviewed alongside them; Daisy and Elaine were interviewed alone with nominated professionals remaining in the building in case they were required. Demographic characteristics are displayed in Table 1.

### 2.3 | Procedure

Consent was obtained following a capacity assessment protocol akin to that of previous researchers,<sup>14,15</sup> whereby an information sheet was read to participants with questions asked throughout to assess their comprehension of the study and their rights as a participant. Demographic data were collected, and an initial interview was conducted with the patient and their caregivers (where appropriate), allowing familiarization with the interviewer, establishing treatment time frames and factual information for subsequent interviews. Pictorial communication aids<sup>16-18</sup> were available for all participants. During an interview debriefing, patients and caregivers were asked to participate in a subsequent interview and to identify any additional caregivers or health care professionals to be interviewed. Recordings of initial interviews were, on average, 17 minutes.

Individual semistructured interviews were arranged and guided by participants with the aim of establishing the patients' experiences of cancer diagnosis, treatment, and survivorship (if appropriate). Caregivers and health care professionals were interviewed separately to supplement and enhance the data collected within patient interviews. Topics included relationships with health care professionals, emotional and practical support, being informed about their

**TABLE 1** Patient demographic details

| Name <sup>a</sup> | Brief narrative                                                                                                                   | Cancer diagnosis        | Treatment(s)                                                                 | Related participant(s)                                                                 |
|-------------------|-----------------------------------------------------------------------------------------------------------------------------------|-------------------------|------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| Adam              | 53, lives with his aunt and uncle and is currently unemployed because of ill-health. Both his mother and father died from cancer. | Plasma cytoma and bowel | Radiotherapy; surgery                                                        | Aunt, uncle, and intellectual disability nurse                                         |
| Ben               | 35, lives with mother and father and is in part-time employment.                                                                  | Testicular and stomach  | Surgery; chemotherapy                                                        | Mother, father, and medical oncologist                                                 |
| Charlie           | 34, lives alone and is seeking part-time employment.                                                                              | Testicular and stomach  | Surgery; chemotherapy                                                        | Social worker                                                                          |
| Daisy             | 76, lives in a residential home (10 residents) and attends a local college part-time. Her mother died from cancer.                | Breast                  | Partial mastectomy                                                           | None                                                                                   |
| Elaine            | 64, lives alone (supported living) and is retired. Familial experience of cancer (cousin).                                        | Breast                  | Lumpectomy; partial mastectomy; preventative double mastectomy; chemotherapy | Social worker                                                                          |
| Freya             | 61, lives in a community group home (3 residents), and is retired. Her mother died from cancer.                                   | Ovarian and lung        | Chemotherapy (palliative)                                                    | Paid caregiver, health liaison nurse, intellectual disability nurse, and social worker |

<sup>a</sup>Changed to ensure anonymity.

illness, and illness-related coping. For each participant, and as the study progressed, interview topic guides were developed to integrate previous findings, for example: (1) some questions (eg, regarding family support) would not be appropriate for all participants, and (2) questions were added to later interviews based on prior interviews. Interviews were audio recorded and transcribed verbatim. Participants were briefly screened for distress as part of a full debrief—no signs of distress were apparent. Patient interviews were on average 22 minutes long, caregiver and health care professional interviews were an average of 32 minutes.

## 2.4 | Design and analysis

Qualitative methodology was considered most suitable for the population and research aims.<sup>17</sup> Specifically, grounded theory,<sup>19</sup> taking a Straussian approach<sup>20</sup> enabling the development of relevant theory and understanding within the existing thin literature. Following the principles of grounded theory, data collection and analysis were concurrent to enable the formation and testing of hypotheses. Transcripts were coded line by line, with relevant concepts and areas for further exploration highlighted and woven into subsequent interviews. The constant comparative method was used throughout, whereby existing and emerging codes were compared with one another until meaningful categories were formed. Following open coding, attention was paid to interrelationships and processual links through axial coding,<sup>20</sup> whereby a grounded theory was emergent from the data.

Analysis was conducted by hand, allowing full emersion and visualization of the data, emergent codes, and categories. Memos and detailed descriptions of data collection, analysis, and write up were undertaken throughout the process. The primary researcher (SF) led the analysis, with regular team meetings to audit, discuss the process, and review emergent codes, categories, and theories, as is considered good practice in qualitative research<sup>21</sup> ensuring transparency and validity. Data collection ceased upon reaching saturation, defined as the point where new codes no longer emerged from the interviews.<sup>19</sup>

## 3 | RESULTS

### 3.1 | Contextual background

Caregivers reported that patients would not express pain or report changes in their physical appearance thus leading to sometimes substantial delays in symptom presentation and diagnosis. Generally, patients had limited symptom knowledge; this was occasionally ameliorated by the delivery of unambiguous, and regular, symptom and health information by caregivers or allied health professionals, ensuring patients were equipped to notice and report potential symptoms.

### 3.2 | Grounded theory: Coping with cancer, or just cutoff?

Relationships between the presented concepts are illustrated in Figure 1, demonstrating the tentative, emergent theory; further exploration of the theory follows.

Following cancer diagnosis, barriers to good *interactions with health care professionals* were reported, as they were often not fully aware of the nature of patients' ID. The interviewed health care professional reported not being educated about ID during medical training. Together with their limited prior experience of this patient group, this often led to a degree of patient invisibility and poor attention paid to additional needs and difficulties:

They didn't realise that Adam had an ID. 'Cause Adam would just nod and say the right sort of things, erm... they didn't really ask him if he wanted to ask any questions or ask him if he wanted anything explaining. They just presumed that he would have taken all this information. (Adam's ID nurse)

Patients were frequently not fully involved in conversations regarding their own illness and treatment. This was generally accompanied by ineffective communication strategies between health care professionals and patients, leading to patients being confused about their own health:

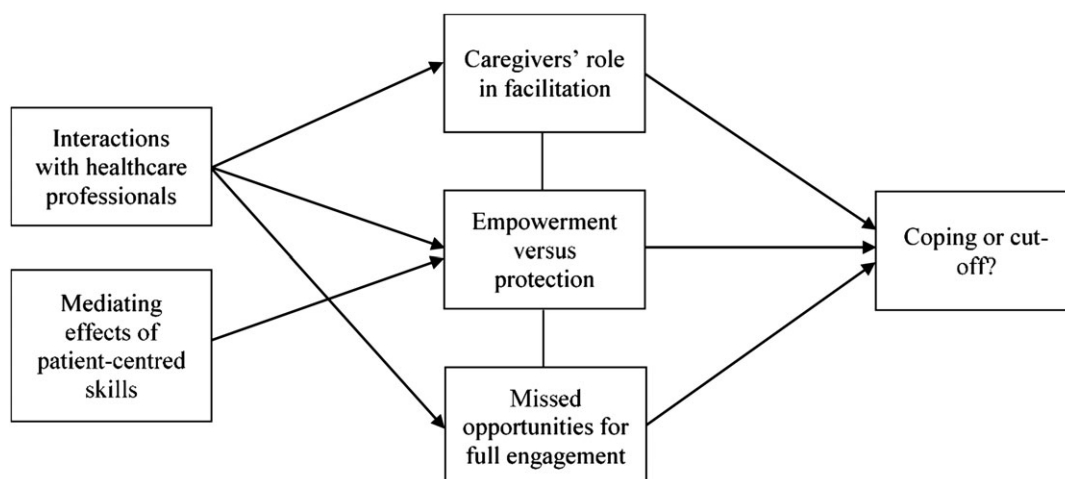


FIGURE 1 Concept map of findings

Freya: I were lying on the bed and he said, coming... 'Why don't we take [your PICC line] out... get rid of it.'

Interviewer: Did he tell you why?

Freya: No, he just said get rid of it.

You don't know... what's got wro... what's gone... what's wrong with you. Cos you can't... you can't... you you... I can't understand what they... the words that they're saying. (Adam)

Regardless of ID knowledge, health care professionals' patient-centered skills (eg, patience, perspective taking, friendliness, and compassion) were of great importance for patients and their caregivers:

Yeah, [the doctors and nurses] were really, really good and helped me through it. (Ben)

But I must say the oncology nurses were very good [...] very understanding, very erm, empathetic and erm... treated Freya with dignity really. (Freya's ID nurse)

Health care professionals possessing these skills would work to the needs of the patient and were better able to communicate in the positive environment that had been fostered. These *patient-centered skills partially mediated the psychologically distressing nature of appointments*; however, the opposite effect was also apparent:

Because Charlie wasn't... didn't feel that he was being included, you see, people were talking at the end of his bed in Welsh. Charlie can't understand Welsh, so Charlie would ring up: 'They're talking about me.' Well quite rightly he'd think that. (Charlie's social worker)

Dependent on the health care professionals' understanding and perceptions, patients were occasionally *empowered* to be involved and make decisions. Patients who were enabled by those supporting them to be involved in appointments were better able to understand and participate meaningfully in their diagnosis and treatment, express their emotions, and subsequently to cope with psychological distress. However, this did not apply to all patients in our study, with the extent of truth-telling inhibited by caregivers' attempts to *protect* patients from psychological distress:

She said 'I'm gonna die like my mum.' And nobody said yes or no to that [...] We weren't going to say yes, we weren't going to say no, we weren't going to lie, we were just going to say 'Everybody is individual, we're gonna give you the medicine and hopefully it will help.' (Freya's Health Liaison Nurse)

*Caregivers' roles in supporting the patient* were often extended by health care professionals who relied on caregivers to facilitate communication and patient inclusion:

[His parents] seemed to be the professionals and I think who could be better at advising us than the

people who live with him and deal with him every day? (Ben's medical oncologist)

However, this support was not always possible or effective. Whilst some attempts were made by caregivers to fully explain the illness to the patient, some caregivers would give up on difficult conversations after only minimal attempts or explicitly inform the patient that they did not wish to have the discussion:

We tried to talk to him sometimes about it, but no. So I thought I'll leave it then, no use pushing it if he doesn't want to talk to it. (Adam's uncle)

[And I would say:] 'But we don't want bring that up, do we? That was a thingy time and erm... we're fine now aren't we?' (Ben's mother)

Humor was commonly used as a communicative device, and in some cases, successful use by health care professionals put the patient at ease:

He said (Laughs) 'Hello trouble!' [...] You know, teasing! He said 'What you... what you done?' [...] I said 'I was in bathroom and I don't know what happened.' (Elaine)

However, in our data, use of humor by caregivers had a different function. Here, it mostly indicated discomfort in having serious discussions with patients and was thus used to diffuse tension:

I think she's quite concerned about the fact that she's becoming so thin. And I always say... 'Ooh, Freya, well look at me with this big fat tummy and a big fat bottom.' You know, 'And there's you like a supermodel!' And she laughs, but she is drastically losing weight (Freya's paid caregiver)

Caregivers' self-protective behaviors and avoidant strategies such as these, whilst potentially adaptive in the short-term, inhibited inclusion (which was greatly valued by patients) often leading to distress as they became more aware of their exclusion from their own cancer experience. As difficult conversations were generally considered taboo, coping, support, and open communication in the long-term were constrained.

It is likely that caregiver perceptions of the patient's ability to cope psychologically with their illness played a role in this judgment, with some caregivers believing that not having a fuller understanding of the illness was protective, reducing the risk of further distress:

I think Ben being, erm... having the problem, the disability... helped him through the cancer, in as much, because he wasn't so aware... of what it does... to a person. (Ben's mother)

Whilst it is not possible in this study to fully explore the impact of *missed opportunities for full disclosure*, it was clear from some interviews that patients who were supported to have a more complete understanding were able to more meaningfully participate in their cancer experience:

Everything was discussed with her, completely. And of course...her [intellectual] disability's quite mild so she was able to consent anyway to...to everything and she understood what was going on. And if she didn't understand, she would always ask [...] I don't know how she found her information out from, but she just seems to...erm...she astounded me actually! (Elaine's ID Nurse)

When opportunities for education and engagement were missed, patients took the view that once their cancer had been treated, they could move on from it; however, they were less likely to remain vigilant of future symptoms, or signs of cancer progression. Additionally, these patients were more likely to convey confusion, anxiety, and frustration in their interviews:

No, because I knew it was a success so I didn't ask questions about it. (Daisy)

No [I don't think about it much], cos as far as I'm concerned. It looks like I have nothing wrong. (Charlie)

I got the back one [plasma cytoma], why did I get the front one [stomach cancer]...it just come like that. I don't know how I get it. (Adam)

Patients' emotions were rarely discussed in any detail by the patient themselves, or those supporting them, and some caregivers felt that they were affected more, emotionally, by the experience than the patients themselves. Caregivers regularly interpreted the lack of emotional expression as an indicator that the patients were coping well, and had not needed to seek emotional support, with most neglecting to ask questions about emotions:

She's quite surprised us really, how well she has coped with everything. (Freya's social worker)

You know, somebody else can...me turning a blind eye to cancer, you know, brushing it under the mat. I think helps him a little bit. I don't know. (Adam's aunt)

This might reflect caregivers' reluctance to engage in potentially difficult conversations; by not asking about emotions, the caregiver is not exposing themselves to a potentially difficult situation in which they do not know how to support problematic patient reactions. In this way, it can be understood as a method of caregiver self-protection, which is then justified as a method of protecting the patient's well-being. Caregivers avoided expressing their own emotions too as a means of protecting patients from this additional burden:

You do have your cry, your rant and...then it's...but not in front of him. [...] I didn't want him to be worried, he's got to cope with enough (Ben's mother)

Although the lack of patients' emotional expression was interpreted by caregivers as evidence of *psychological coping*, an alternative explanation might be that patients *knowingly disengaged*

from negative emotions, or modelled their behavioural and emotional responses to cancer on those of their caregivers:

I think he looked to us, actually...to see how we reacted to it...to what...how he should, how he should take it. It's happening to him, obviously, but because he's so easy going and may not comprehending the serious of it, [...] he was picking up from us...how he... how he was gonna feel almost. (Ben's father)

Overall, our data suggest that caregivers' attempts to protect patients from negative emotional responses are misplaced. When patients were supported to understand and cope with the consequences of that level of understanding, they had no more difficulty coping than would be reasonable for anyone diagnosed with cancer:

I really didn't know how she would cope with it. But she absolutely coped with it...fantastically, and in as much as I think if I ever had to go through it with anybody else, I'm sure she...if I asked her, she would... she would be quite a good source of erm...comfort or...erm, information for somebody else who'd been in a similar situation. (Elaine's ID nurse)

## 4 | CONCLUSIONS

The present research aimed to establish the cancer-related experiences of six people with ID, with data from the individuals themselves, related caregivers, and health care professionals.

Emergent core concepts were not entirely dissimilar to what might be expected in an exploration of psychological adjustment to cancer in the general population: causes for delays in symptom presentation,<sup>22</sup> barriers to communication and understanding,<sup>23</sup> caregiver burden,<sup>24</sup> and high levels of patient distress and ineffective coping.<sup>25</sup> With this sample, however, the degree and incidence of psychological and supportive care difficulties appear much greater, with patients facing barriers at most points during their treatment. Evidence of health inequalities is not uncommon for people with ID,<sup>7</sup> and the present data suggest that this inequality applies particularly to cancer care.

Our findings suggest that empowerment is important for patient engagement, and in community samples, patient involvement is expected. Self-determination can be learned by people with ID,<sup>26</sup> indicating that with the right level of support, many people with ID can be as involved with their illness and treatment decisions as any other person. This is supported by previous research that reports that when healthy people with ID are engaged in their own care and enabled to participate meaningfully, their psychological well-being can be greatly improved.<sup>27</sup>

Further to this, there is a current movement within ID care provision to involve people as partners in their own health care (eg, Check 4 Change, with Macmillan and Carmarthenshire People First in Wales, UK), and our data support such initiatives. Individual involvement in health care provision will obviously differ between



patients and must be planned in accordance with comprehension ability and capacity; the Mental Capacity Act 2005 provides an essential framework when providing care to patients with ID. To ensure wider patient inclusion, reasonable adjustments (including accessible information, understandable communication, and developing an inclusive care plan) should be made and tailored to each persons' needs.<sup>28,29</sup> Previous research has demonstrated that comprehension of information is impacted by ID severity and previous life experiences, but most importantly, the extent to which the person is supported to understand.<sup>30</sup> Therefore, it is imperative for oncology (and related) services to support all cancer patients with ID to fully understand relevant information to their health and health care.

In previous work, oncology nurses perceived themselves as lacking confidence and being insufficiently trained to recognize and meet the needs of cancer patients with ID,<sup>31</sup> potentially leading to difficulties being unintentionally overlooked and unmanaged. It was also found that they would feel more comfortable communicating with a caregiver instead. The present study highlighted the reliance on caregivers—particularly family members—for delivering medical information that may be unfamiliar to them and this is not ideal. Whilst it is difficult to ensure best practice in this area, for example, because of time pressures,<sup>32</sup> possessing good patient-centered skills can enable health care professionals to optimize their consultation time. Interventions targeted at improving these skills,<sup>33</sup> which encompass improving knowledge of specific needs of people with ID,<sup>34</sup> would likely be beneficial. Theoretically, patient-centered skills such as these should be transferable between patient populations; interventions that enhance consultations with patients with ID may thus generalize to patients with other comprehension or communication difficulties (eg, patients with dementia) or to those with a different first language to the health care professional. Such interventions should be empirically sound and easily implementable to everyday practice.

Caregivers' burden was compounded by the reliance on them as experts by health care professionals. It is well accepted that multidisciplinary working<sup>35</sup> and family involvement<sup>36</sup> are positive features in health care, but many caregivers in our sample would have benefitted from being supported themselves. Caring for carers in this way is known to have consequential positive effects, for example, by enabling them to feel better able to support the patient.<sup>37</sup> Psychological support was occasionally offered to patients in this study; more benefit could be achieved in practice by providing similar support to primary caregivers too.

In the present work, caregivers felt uncomfortable and unprepared to support the patient, often attempting to protect the patient from negative effects of cancer, by limiting truth-telling. Our data support the idea that much communication regarding death and dying is inhibited by implicit or euphemistic language,<sup>38</sup> potentially causing understanding difficulties for people with ID. Related to this is the idea that the emotional expression of people with ID is often overlooked by carers.<sup>39</sup> To fully support patients (whether with or without ID), it may be necessary to foster an open and safe communication space in the clinical setting for the discussion of difficult topics, but this was not always the case in our sample.

## 4.1 | Study evaluation

Whilst only six patients were recruited into this study, and interviews were relatively short, patients were demographically broad, with regard to sex and age, and saturation was reached at this point. The study offers a novel contribution for our understanding by including the broader patient support network in the same study; this enabled us to take a multiple stakeholder view of the care experiences of this patient group. Only patients with mild ID were admitted to the study (this was due to ethical restrictions meaning that patients must have the capacity to consent to participate); however, it is reasonable to assume that similar difficulties will be present and persistent for people with more severe ID, and so efforts to include a more heterogeneous sample in future research would be beneficial. Of course, communication difficulties, both for researchers and clinicians, are likely to become more pronounced in accordance with the level of ID. Although every opportunity to include patients was made, including using alternative communication strategies (eg, visual aids), patient data were occasionally not sufficiently rich; this was supplemented with caregiver or health care professional data. However, this was not always possible (ie, Daisy was interviewed in isolation, because of her diagnosis being relatively historic and not being in contact with any of her previous caregivers or health care professionals). More widely, health care professionals were not often identified by patients to be approached for an interview; in fact, only one was identified, approached, and interviewed. It is therefore integral to gain a more complete understanding of health care professionals' experiences in caring for this patient group.

One of the key features of grounded theory research is the ability to generate theories and hypotheses for future work.<sup>40</sup> Based on the theory presented, future research should extend and validate these findings, particularly regarding the strategies used by caregivers and health care professionals for noticing the emotional impact and potential psychological distress in patients with ID, and how best to support them through this difficult experience. This should include, but not be limited to, explorations of the influence of caregivers on care provision and means of breaking down barriers to successful support. Such research should be patient-focussed and aim to facilitate the needs of patients, caregivers, and professionals alike. Potential interventions could focus on increasing health care professionals' knowledge, confidence, and communication skills in working with people with ID, particularly concerning difficult health care conversations and decisions.

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## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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