



## A narrative literature review examining cancer treatment issues for patients living with intellectual disabilities

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### ABSTRACT

**Purpose:** The experiences of cancer care can be mediated by many different factors and this narrative literature review aims to explore the experiences of cancer care in relation to people with intellectual disabilities receiving cancer treatment.

**Method:** We undertook a search for articles in English from (Jan) 2000–(Feb) 2018 using Medline, CINAHL, ScienceDirect, ASSIA and Wiley. The inclusion criteria are 2000–2018, English language and focussing on experiences of cancer journey. We used a narrative approach and thematically analysed the data.

**Results:** There were 10 papers that met our inclusion/exclusion criteria. The themes generated included communication issues, information giving and decision-making. The literature suggests that communication and decision-making within cancer care are often mediated through support workers or family carers with minimal involvement of the person with intellectual disabilities. Information-giving by health professionals and support workers to people with intellectual disabilities was limited. This was often justified by the perceived distress this may cause.

**Conclusion:** Training for health professionals and support workers in supporting people with intellectual difficulties is required for more effective communication in cancer care.

### 1. Introduction

There is evidence that within the United Kingdom (UK) patients with cancer and a chronic condition or disability (including, for example, deafness/hearing impairment, blindness/partially sighted, intellectual disability and mental health conditions) are less likely to perceive their cancer care as “excellent” or “very good” (Bone et al., 2014). The variation remains even after taking account of clinical factors such as cancer type, duration of treatment and hospital level factors. Bone et al. (2014) suggest that this is related to clear differences in experiences among these groups. Miller et al. (2014) highlight that, from a health professional perspective, discrimination and bias are a perceived disparity in cancer care. They also report better outcomes for those patients with well-established social support. Those patients with intellectual disabilities (ID) may have limited social networks making care provision more challenging (Sinding, 2004). There are increasing numbers of people with ID and cancer, in part, due to increased longevity (for example, within England an increase by 53% of those > 50 years age range between 2001 and 2021) (Emerson and Hatton, 2008). There are a number of organisational barriers for people with ID in accessing healthcare services. These include limited service provision as

well as physical barriers (Emerson, 2011). There are also barriers related to health literacy and communication challenges for people with ID (Michael, 2008). This has resulted in individuals with ID being excluded from General Practitioner (GP) consultations (Ward et al., 2010; Wullink et al., 2009). There are also issues of diagnostic overshadowing (Jopp and Keys, 2001). Diagnostic overshadowing occurs when symptoms related to physical health are mistakenly misinterpreted as behaviours typically associated with a diagnosis of intellectual impairment (Ovellette-Kuntz, 2005). Attitudes of staff were also instrumental in the health care experience of people with ID (Alborz et al., 2003, 2005; Ali et al., 2013). There is evidence that doctors do not understand the health needs of people with ID (Ward et al., 2010) and this has contributed to diagnostic overshadowing (Webber et al., 2010; Dinsmore, 2012). Although people with ID attend their GP at similar levels to the general population their health is less likely to be monitored (Emerson et al., 2011) and this includes receiving health promotion and screening services (Broughton and Thomson, 2000). Given the high degree of health problems with people with ID (Emerson and Baines, 2011) and in comparison to GP consultation rates for other groups of patients who also have chronic conditions, people with ID have lower attendance rates (Felce et al., 2008). There have also been

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studies highlighting the lack of support for patients with ID in general hospitals, including poor communication strategies by health professionals (Gibbs et al., 2008). People with ID who also have cancer are often not told of both their diagnosis and prognosis, nor referred for specialist palliative care or given adequate pain relief (Tuffrey-Wijne et al., 2010; Bernal and Tuffrey-Wijne, 2008). The aim of this literature review is to explore the experiences of cancer care in relation to people with ID receiving cancer treatment. We have chronicled the research evidence within this area highlighting both issues that are pertinent to clinical practice and gaps in the evidence base with suggestions of future research.

## 2. Methods

We used a narrative approach producing an interpretive review, involving “the selection, chronicling and ordering of evidence to produce an account of the evidence” (Dixon-Woods et al., 2005; 47). This approach was taken due to the quality, scarcity and diversity of the literature retrieved with less emphasis on evaluation criteria and methodological matters than other forms of review (May et al., 2005).

### 2.1. Search strategy

We undertook a search for articles in English from the databases and search terms described in Table 1. We searched from (Jan) 2000–(March) 2018 to capture the limited range of papers within this subject area. Reference lists of relevant articles were also searched to identify related studies. The database searches and hand searches were undertaken following the PRISMA guidelines (Moher et al., 2009). After title and abstract review and the removal of duplicates and non-research papers, the remaining full-text papers were retrieved and scrutinised (n = 49). The application of the inclusion criteria further limited the number of papers to 10 (Fig. 1).

### 2.2. Inclusion & exclusion criteria

Inclusion criteria were that papers were empirical, peer-reviewed, focussed on aspects of the treatment cancer journey for patients with ID and their formal or informal carers. Papers were from 2000 to 2018 and in English. Exclusion criteria related to papers predominately reporting on cancer prevention or detection, risk/prevalence studies (pre-diagnosis), palliative care focused or review papers.

### 2.3. Quality appraisal

Studies were assessed for quality using the screening tool developed by Hawker et al. (2002) with both authors independently rating the papers. This checklist appraises data on abstract and title, introduction and aims, methods and data, sampling, data analysis, ethics and bias, results, transferability or generalisability, implications and usefulness. Scores range from 9 (very poor) to 36 (good) and indicate the methodological rigour for each paper (see Table 2). As each paper was assessed by two researchers, a mean score for each paper was calculated. Studies were not excluded on the basis of the quality appraisal but

**Table 1**

Search terms.

Databases searched: MEDLINE (Web of Knowledge), CINAHL, SCIENCE DIRECT, ASSIA (ProQuest), WILEY
Search terms:
Cancer AND “learning disabili*”
Cancer AND “intellectual disabili*”
Cancer AND “intellectual disabili*” AND carer*
Cancer AND “learning disabili*” AND carer*
Cancer AND “learning disabili*” AND famil*
Cancer AND “intellectual disabili*” AND famil*

rather this process illustrates the methodological strengths and weaknesses of each study included.

### 2.4. Data synthesis

The papers were analysed thematically to systematically search for commonalities and themes to describe the data (Braun and Clarke, 2006). The first author reviewed each paper and data was coded to describe the study findings. Similar codes were grouped together into categories or themes to explore the relationships between and within studies. New categories were developed or modified as analysis continued and a coherent and detailed synthesis emerged.

## 3. Results

After application of the inclusion/exclusion criteria 10 papers were included in this review (Table 2). All the papers (except for Flynn et al., 2015 and Sullivan and Hussain, 2008) were qualitative in design, from focus groups (Witham et al., 2014) to participant observation (Jones et al., 2006; Tuffrey-Wijne et al. 2009, 2010), case study, narrative life story approaches (Martean et al., 2013; Tuffrey-Wijne and Davies, 2007; Cresswell and Tuffrey-Wijne, 2008) and interviews (Flynn et al., 2016). Flynn et al. (2015) used questionnaires based on vignettes to explore stigma and to assess attitudes and care perceptions of UK oncology nurses, whilst Sullivan and Hussain (2008) analysed hospital data sets to establish hospital admission for cancer and co-morbidity for people with ID.

### 3.1. Communication challenges

Communication issues were a common theme throughout the papers. Complex communication challenges were often exacerbated by the dependence of people with ID on others (Tuffrey-Wijne et al., 2009; Martean et al., 2013; Flynn et al., 2016). Triadic relationships between carers or support workers, health professionals and the person with ID meant effective communication was predicated on all parties being able to articulate the issues and concerns in an inclusive and understandable way. This was within the context of complex decision-making about appropriate cancer treatment, issues of quality of life and potential side effects in addition to prognostic judgements related to outcomes (Tuffrey-Wijne and Davies, 2007, Jones et al., 2006, Cresswell and Tuffrey-Wijne, 2008, Tuffrey-Wijne et al., 2009, Witham et al., 2014). Martean et al. (2013), for example, suggest that carers and families of people with ID, who present with psychological distress may encourage happiness or “forced jolliness” (Tuffrey-Wijne et al., 2010; 228) and minimise the concerns of the person with ID. Martean et al. (2013) refer to the ‘handicapped smile’ (Sinason, 1992) where people with ID learn to mask distress from others and conform to the cultural requirement to be positive. In terms of information giving by support workers to the person with ID, Tuffrey-Wijne et al. (2009) suggest that it was based on what the support worker would want themselves. This was coupled with a lack of confidence from the support worker in their ability to explore the issues in a meaningful way and a desire to protect the person with ID and cancer from distress. Tuffrey-Wijne et al. (2009) further suggest that health professionals often disregarded or misinterpreted their interactions with someone with ID. They had a limited awareness of the tendency for people with ID to acquiesce. This led to assumptions about a person’s comprehension and ability to understand cancer treatment (Tuffrey-Wijne et al., 2009, 2010; Martean et al., 2013; Flynn et al., 2016). Communication by health professionals to the person with ID was limited with most discussion on cancer treatment and care issues mediated through support workers or family irrespective of severity of the ID (Martean et al., 2013, Flynn et al., 2015, 2016). Flynn et al. (2015), for example, indicate from their sample of oncology nurses that none of the participants reported that they would consult the patient themselves about how best to support them. Some studies

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