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Caring for cancer patients with an intellectual disability: Attitudes and care perceptions of UK oncology nurses



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A B S T R A C T

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Purpose: Caring for people with cancer or an intellectual disability (ID) is stressful: little is known about the combined impact of caring for cancer patients with an ID, though this is expected to be especially challenging.

Method: Eighty-three nurses, working in oncology or a related field (i.e. palliative care) were recruited. Perceptions of caring for patients with and without an ID were measured, alongside potentially confounding information about participant demographic characteristics and perceived stress.

Results: Participants felt less comfortable communicating with patients with an ID about their illness ($F(1,82) = 59.52, p < 0.001$), more reliant on a caregiver for communication ($F(1,82) = 26.29, p < 0.001$), and less confident that the patient's needs would be identified ($F(1,82) = 42.03, p < 0.001$) and met ($F(1,81) = 62.90, p < 0.001$). Participants also believed that caring for this patient group would induce more stress, compared with patients without an ID ($F(1,81) = 31.592, p < 0.001$). Previous experience working with ID patient groups appears to mitigate some perceptions about providing care to this population.

Conclusions: Caring for cancer patients with an ID may intensify this, already difficult, role. Through training and knowledge exchange, oncology nurse's confidence in communication, providing appropriate care, and positivity towards this patient group may be improved.

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Introduction

Providing nursing care for cancer patients can be emotionally demanding (Emold et al., 2011). Nurses are at an elevated risk of stress, job dissatisfaction and burnout, heightened by perceived staff shortages (Toh et al., 2012). Caring for individuals with an intellectual disability (ID) can also be particularly challenging for healthcare professionals (Mutkins et al., 2011; Skirrow and Hatton, 2007) with high potential for stress and burnout (Lin and Lin, 2013); and is associated with incidents of challenging behaviour (Hensel et al., 2012; Mills and Rose, 2011) and perceived role conflict or ambiguity (Vassos and Nankervis,

2012). Over time, more people with an ID are being diagnosed with cancer, in part due to increased life expectancy (Hanna et al., 2011); thus oncology nurses, among other healthcare professionals, are supporting more patients with additional needs and communication challenges. Given that caregiver stress is prevalent for cancer and ID professionals, it stands to reason that additional difficulties will arise when providing care for a cancer patient with an ID.

Successful communication is vital when caring for cancer patients (Arora, 2003; Kissane et al., 2012); however research demonstrates that when caring for a patient with complex communication needs, nurses find their ability inhibited by time constraints (Hemsley et al., 2012). Discussions about consequences of cancer treatment may include intimate care concerns; Turk et al. (2012a) report discomfort for both the interviewer and interviewee (with an ID) when discussing such issues. Communication

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difficulties may, therefore, lead some healthcare professionals to communicate with a caregiver rather than the patient directly (Gibbs et al., 2008; Ryan et al., 2011); although, this information is not always accurate and congruent with information otherwise provided by the patient (Turk et al., 2012b), potentially leading to misinformation and miscommunication.

Communication is just one area of cancer care: healthcare professionals may feel unprepared to provide other aspects of care to people with an ID (Stein, 2008), and be unaware of best practice guidelines in ID care (Ryan et al., 2011). Strategies to facilitate multi-disciplinary working have been suggested, however, Ryan et al. (2010) report communication between ID and palliative care staff to be infrequent and ineffective.

This research aimed to investigate the previously unexplored perceptions of oncology nurses regarding the provision of cancer care for patients with and without an ID; it was hypothesised that participants would feel more positively about providing care for patients without an ID. As secondary research questions we explored whether (a) providing care for patients with an ID would be more stressful than for patients without an ID, and (b) there were any differences in perceptions of patient communication between patients with and without an ID. Exploratory analysis was undertaken to discover any interaction effects, whereby participant demographic characteristics (e.g. previous ID experience) impacted participant perceptions following the ID and non-ID vignettes.

Method

Participants

Participants were nurses working in oncology or a related field (i.e. palliative care), and were members of the UK Oncology Nursing Society (UKONS). All 2309 UKONS members were invited to participate; 138 people responded, with 83 participants (Table 1) fully completing the questionnaires.

Table 1
Participant demographic details.

	N (%)
Gender	
Female	81 (97.6)
Male	2 (2.4)
Age	
18–24	1 (1.2)
25–34	9 (10.8)
35–44	27 (32.5)
45–54	39 (47)
55–64	7 (8.4)
Highest Qualification	2 (2.4)
Diploma	9 (10.8)
BSc/BA Degree	40 (48.2)
Graduate Diploma	9 (10.8)
MSc/MA Degree	20 (24.1)
PhD	3 (3.6)
Employment Type	
Full-time	68 (81.9)
Part-time	14 (16.9)
Missing	1 (1.2)
Employment Sector	
NHS	75 (90.4)
Private	5 (6)
Charitable Organisation	2 (2.4)
Research Organisation	1 (1.2)
ID Experience	
Yes	61 (73.5)
No	22 (26.5)
Mean Perceived Stress Score (Max. = 40)	18.54

Materials

Vignettes

Using vignettes, particularly when exploring stigma (e.g. Scior, 2011), is a common and effective approach which allows researchers to gauge, with relative accuracy, the perceptions and beliefs of a participant group regarding a specific situation (Braun and Clarke, 2013); and has applications to healthcare provision and nursing (e.g. Wandner et al., 2014). Vignette studies are of particular use within potentially sensitive research; less direct than traditional questionnaires, the participant is encouraged to construct a realistic reaction to a hypothetical situation (Braun and Clarke, 2013).

The vignettes and accompanying care perception questions were devised by the researchers. Four vignettes described patients, with two slightly different versions of each; additional information was included in one version of each vignette, indicating that the patient had an ID (Box 1). Vignettes were randomly assigned to participants; with each participant receiving four different vignettes (two ID and two non-ID); for instance, if vignettes A and D

Box 1

Example vignettes.

Vignette D

Non-ID version

Paul is 48 and has colon cancer. He lives alone and is not married; he attends all of his appointments on his own as his family do not live close enough to help him. Despite this, he is a happy man who enjoys discussing sports with other patients and staff alike. He is determined to overcome his illness and doesn't moan about the treatments, even though it is apparent that he is experiencing some pain and discomfort. He asks questions during his appointments and seems to understand and accept the answers which are given to him, however some other health care professionals have highlighted that they are not sure whether he does fully understand everything that is said to him.

ID version

Paul is 48 and has colon cancer. He also has a mild intellectual disability. He lives alone and is not married; he attends all of his appointments on his own as his family do not live close enough to help him. Despite this, he is a happy man who enjoys discussing sports with other patients and staff alike. He is determined to overcome his illness and doesn't moan about the treatments, even though it is apparent that he is experiencing some pain and discomfort. Paul can struggle with some aspects of self-care; he has a paid carer who assists him twice a week. He seems to understand and accept the information which is given to him, however some other health care professionals have highlighted that they are not sure whether he does fully understand everything that is said to him. Paul sometimes gives an unrelated answer to questions asked by health care professionals; some colleagues have mentioned that it can be very difficult to find out important information.

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