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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.

described a patient with an ID, the patient in vignettes B and C would not have an ID.

Following each vignette participants answered twelve questions, measuring care perceptions and attitudes (detailed in Table 2); responses were measured on a 5-point Likert scale, ranging from “1 – Strongly disagree” to “5 – Strongly agree”. Participants were then asked to consider generally providing care to a patient with an ID and to answer two open-ended questions: “If you were unsure about how to provide the highest quality care for this patient, would you know where to go for advice? Where would that be?” and “Are there any additional training needs you believe would be beneficial to help provide care to this person?”

Perceived Stress Scale

Developed by Cohen et al. (1983), the Perceived Stress Scale (PSS) is a 10-item self-report measure. Items include: “In the last month, how often have you felt nervous and “stressed”?” and are scored on a 5-point Likert scale (“0 – Never” to “4 – Very Often”). Four positive questions are reverse scored, and the responses totalled; a high score indicates a high level of perceived stress. Within this study, the PSS has high reliability ($\alpha = 0.84$); consistent with other research ($\alpha = 0.82$; Andreou et al., 2011).

Procedure

Ethical approval was received from a University Ethics Committee; the UKONS Board approved the study for circulation to members. Participants received an email invitation from UKONS including: a brief study explanation, researcher contact details and a link to the study. Upon accessing the study webpage, participants read the information sheet, and indicated consent by clicking through to the next page, before completing the questionnaires. Once completed, participants were shown a debrief page which included signposts to further support if needed.

Analysis

Each participant's scores for all twelve questions regarding their care perceptions for both viewed ID vignettes were totalled, and a

mean score was calculated; total and mean scores were also calculated for the questions regarding the non-ID vignettes. A series of two-way within-participants ANOVAs tested the main effects of vignette type (ID or non-ID) on participant's care perceptions. Exploratory analysis to discover any interaction effects with other variables (e.g. previous experience of ID patient groups) was undertaken using 2×2 mixed measures ANOVAs.

Responses to the two open-ended questions were thematically coded, drawing categories from the data, and analysed quantitatively using descriptive analysis to establish additional training needs and advice seeking suggestions.

Results

Care perceptions

Significant main effects of vignette type (ID or non-ID) were found for all twelve questions measuring care perceptions (Table 2); indicating that participants felt more confident in their knowledge, training and experience, better able to identify and meet the needs, and communicate with patients without an ID. Participants held more positive perceptions about patients without an ID and felt that caring for a patient with an ID would cause them to feel more stressed. Most differences between ID and non-ID care perception questions had a large or medium effect size (Cohen, 1988), indicating that the means for these care perceptions were substantially different. The difference in responses to one care perception (understanding the patient's circumstances) had a small effect size ($d = -0.46$); thus the difference in means was marginal.

Interaction effects

Significant interaction effects were discovered whereby participants who had previous ID experience felt that they possessed more relevant knowledge ($F(1,81) = 7.670, p = 0.007$) and experience ($F(1,81) = 6.992, p = 0.01$) when providing care for a patient with an ID than participants with no experience. These participants were also more confident in meeting the needs of patients with an ID ($F(1,80) = 4.314, p = 0.041$) and felt more positively about

Table 2
Mean scores, analysis of variance and effect sizes for care perception questions.

Care perception question	ID vignettes	Non-ID vignettes	Difference between ID and non-ID (<i>F</i>)	Effect size (Cohen's <i>d</i>)
I believe that I have the sufficient level of knowledge to provide care for this patient.	3.69 (0.78)	4.20 (0.59)	(1.82) 36.80 ^a	–0.74
I believe that my previous nursing experience will assist me in providing care for this patient.	3.92 (0.74)	4.42 (0.46)	(1.82) 41.25 ^a	–0.81
I believe that I have received sufficient training to provide the highest quality care to this patient.	3.34 (0.94)	3.86 (0.82)	(1.82) 42.76 ^a	–0.59
I believe that I would be able to successfully communicate with this patient.	3.74 (0.60)	4.33 (0.52)	(1.82) 60.50 ^a	–1.05
I feel comfortable talking to this patient about their illness.	3.79 (0.70)	4.37 (0.54)	(1, 82) 59.52 ^a	–0.93
I would be dependent on the person accompanying the patient to communicate with the patient.	2.70 (0.84)	2.16 (0.87)	(1.82) 26.29 ^a	0.63
I feel confident that the needs of this patient would be identified.	3.43 (0.74)	3.98 (0.60)	(1.82) 42.03 ^a	–0.82
I feel confident that the needs of this patient would be met.	3.38 (0.69)	3.92 (0.58)	(1.81) 62.90 ^a	–0.85
I understand this patient's circumstance.	3.37 (0.88)	3.79 (0.93)	(1.81) 28.17 ^a	–0.46
I feel positively about providing this patient with care.	3.85 (0.64)	4.27 (0.57)	(1.81) 39.54 ^a	–0.69
I feel confident that I would be able to provide this patient with the appropriate care.	3.77 (0.64)	4.22 (0.58)	(1.80) 37.81 ^a	–0.74
I believe that providing care for this patient would cause me to become stressed.	2.71 (0.89)	2.26 (0.88)	(1.81) 31.59 ^a	0.51

^a $p < 0.001$. Standard deviation is in parentheses alongside the mean score.

providing care ($F(1,80) = 11.458, p = 0.001$). Participants with previous experience felt more confident in providing appropriate care for patients with an ID ($F(1,79) = 6.663, p = 0.012$) and believed that they would become less stressed when providing this care than participants with no previous experience ($F(1,80) = 6.263, p = 0.014$).

Participants with no previous ID experience felt that they had received more sufficient training to care for a patient without an ID than with an ID, this difference for participants with previous experience was less evident ($F(1,81) = 6.381, p = 0.013$). Additionally, participants with no prior experience felt that they were better able to understand the circumstances of patients without an ID; this difference was less prominent for participants with previous ID experience ($F(1,80) = 4.928, p = 0.029$).

No statistically significant interaction effects were found for successful and comfortable communication with the patient, or for identifying the patient's needs. Other demographic characteristics were also considered: age, gender, level of education, perceived stress, whether participants were employed full or part time, and what sector they worked in. Gender was not included in the exploratory analysis as there were only two male participants. None of the remaining characteristics were found to impact any of the care perception questions.

Seeking advice and training needs

Seeking advice

Of 78 participants to answer this question, 64 participants made 107 suggestions regarding where they would seek advice when caring for a patient with an ID; these were coded into wider categories. One participant stated that the specific circumstances and needs of the patient would determine where they would seek advice (see Fig. 1).

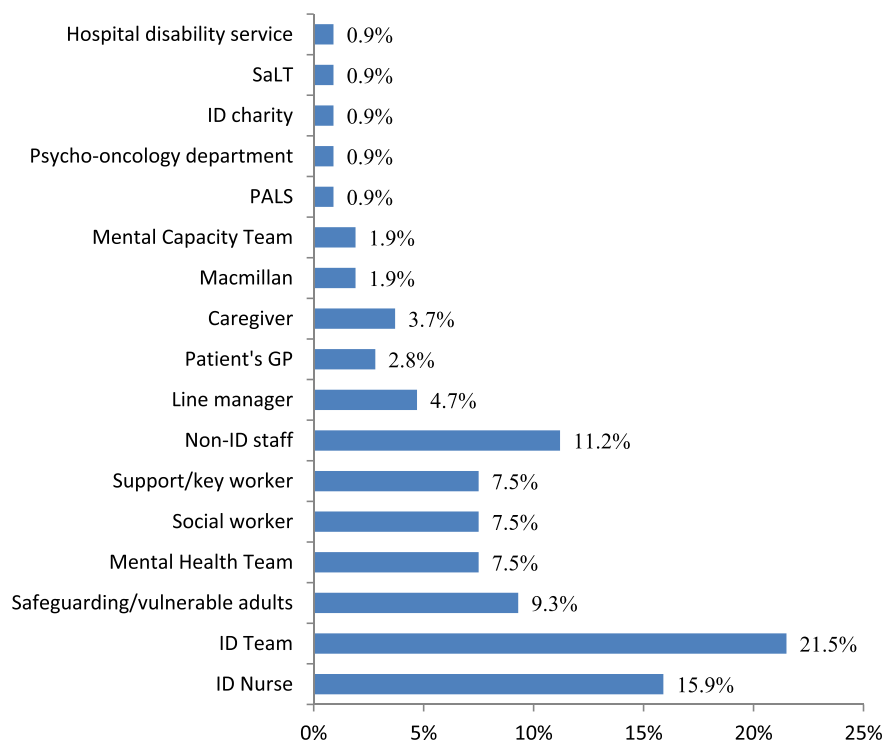


Fig. 1. Participant identified sources of advice when caring for a patient with an ID, PALS: Patient Advice and Liaison Service, SaLT: Speech and Language Therapist.

Additional training needs

In total, 46 participants responded to this question, making 56 suggestions of additional training needs for providing care to a patient with an ID (Fig. 2).

Discussion

This study aimed to explore the perceptions held by oncology nurses when caring for patients with and without an ID. Secondary aims were to investigate confidence levels when caring for this group of patients and whether this would lead participants to feel more stressed in their work. Potential interaction effects between care perceptions and participant demographic characteristics, including current stress levels, were also investigated; previous experience of caring for an individual with an ID was the only significant variable within this exploratory analysis.

Care perceptions

As hypothesised, oncology nurses felt less positive and confident about providing care to patients with an ID, including reporting having less relevant knowledge, training and experience for caring for this patient group. Similar results have been reported in other populations, for instance palliative care professionals often lack confidence in supporting people with an ID (McIlfratrick et al., 2011; Stein, 2008), and are unaware of best practices (Ryan et al., 2011). Cancer patients will often have high expectations of oncology nurses (Sapir et al., 2000) thus, it is imperative that they understand how to meet the needs of all patient groups, or be able to access training to facilitate their understanding. Our study provides valuable insight into the confidence levels of oncology nurses, and suggests that this is lacking when considering the care of patients with an ID.

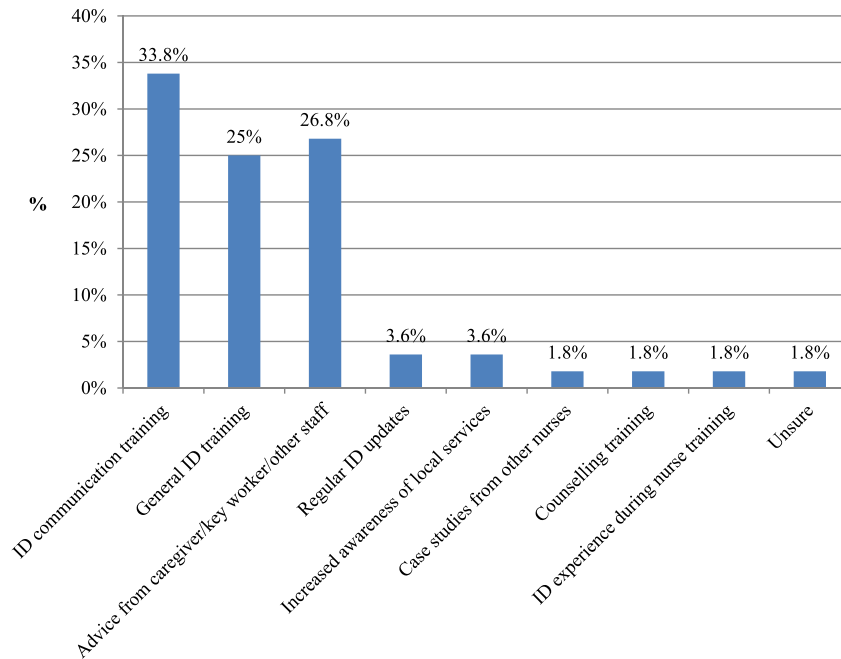


Fig. 2. Participant identified additional training needs for caring for patients with an intellectual disabilities.

Perceiving oneself to have the necessary knowledge to provide appropriate care is vital (Ward and Wood, 2000), especially to patients with additional needs. In the Healthcare for All report (Michael, 2008) it was recommended that all healthcare professionals should receive compulsory ID training; however there is no evidence within the literature or in the data presented in this study to suggest that this is being undertaken. Education courses can improve knowledge, self-perceived psychosocial care skills, and preparedness for nursing cancer patients (Steginga et al., 2005); such interventions could be tailored to educate nurses about meeting the needs of diverse patient groups, including those with an ID.

In addition to reporting low caregiving confidence, our sample felt less comfortable communicating directly with patients with an ID, and suggested that they would rely more on communicating with the patients' caregiver. This finding supports previous work which highlighted the difficulties faced by healthcare professionals when caring for patients with an ID, and the reliance of these professionals on ID carers for information and support (Murphy, 2006; Turk et al., 2012a). Whilst carers are undoubtedly important figures for patients with communication difficulties, it is imperative that oncology nurses also feel able to converse with patients directly. The reliance of proxy reports, such as those from carers, can be problematic and often lead to a disproportionate number of health problems being reported by carers than would be by the patient themselves (Turk et al., 2012b). Though it may be necessary to obtain supplementary information from a caregiver, the Mental Capacity Act 2005 guidelines state that it is best practice to speak directly to the individual; with all patients being involved and fully informed about treatment decisions, with the assistance of additional resources as appropriate.

Stress and burnout for both cancer and ID professionals is relatively high (Emold et al., 2011; Mutkins et al., 2011), thus it is unsurprising that our participants felt that they would be additionally burdened by a cancer patient with an ID. The perceived shortage of knowledge, experience and confidence when caring for this patient group may well have contributed to this perception. This is supported by the wider literature, whereby it was reported that accident and emergency nurses felt that they lacked knowledge when caring

for patients with an ID, which led to them being fearful of communication and care provision to this patient group (Sowney and Barr, 2006). It is evident that emotions related to supporting a cancer patient with an ID are complex; further exploration should aim to facilitate a broader understanding of the emotional impact of providing care to this population (including feelings of stress) on oncology nurses, among other oncology professionals.

Previous experience and training needs

Participants with previous experience of working with people with ID felt more positively about meeting the patient's needs, providing appropriate care, and feeling additional stress when providing care to this patient group, than did participants with no such prior experience. Previous research has found that increased familiarity and understanding of people with an ID can reduce anxiety when providing care (Li et al., 2012); and a recent literature review (Ryan and Scior, 2014) of 24 studies, in which interventions aimed to improve medical students' attitudes towards patients with an ID, found that most studies had positive effects. Ryan and Scior noted that findings were not unanimous across all studies, and that some interventions were methodologically limited (e.g. they did not employ stringent measures and control groups were often absent), which should be noted for future research. However, given that these interventions were effective in a group who had no prior experience of working with ID populations, similar work exploring their efficacy in oncology nurses would be a valuable addition to the literature. This may not only improve care perceptions, but also decrease the associated anxiety, uncertainty and perceived burden when caring for this population. Future studies should attempt to discover the most effective form of training to improve nurses' attitudes and care perceptions (e.g. educational, practical, or a combined approach) as the results may potentially benefit not only the patient, but also the wellbeing of carers and healthcare professionals.

Most participants in our study reported that they would seek advice from another professional (e.g. ID team, ID charity, additional needs professional, line manager) to supplement their own

experience and knowledge, this has the added benefit of providing peer-support within the workplace. Multi-disciplinary team (MDT) working is common within both cancer (Rajan et al., 2013) and ID (Balogh et al., 2008) care, but communication *between* ID and some oncology specialist teams (e.g. palliative care) has been previously reported to be problematic (Ryan et al., 2010). Having a strong network of managers and support from other staff is beneficial to overall emotional and practical functioning (Aycok and Boyle, 2009; Davis et al., 2013) and may be especially helpful when caring for populations with additional needs.

Many sources of inter-professional support would only be applicable in certain circumstances, for instance, making contact with a social worker would only be appropriate if the patient was already known to them, or had circumstances whereby their input would be necessary. Nineteen participants in this study (22.9%) were either unsure of where to seek specific advice, or did not answer this question at all; a small proportion of participants indicated that they would contact a mental health team. That these participants did not appropriately differentiate between an ID and a mental health condition is concerning as both uncertainty and inappropriate advice seeking may lead to inappropriate or inadequate support being provided, thus further impacting on the healthcare experience of a patient during an already distressing time. There is a clear role for educational interventions targeted at oncology professionals in not only meeting the needs of patients, but also in knowing how to appropriately seek advice and signpost when caring for patients with additional ID needs.

None of the participants reported that they would consult the patient themselves about how best to support them, despite evidence that people with an ID value involvement in their own healthcare decisions (Tuffrey-Wijne et al., 2007). This corresponds with our earlier finding that participants felt less confident communicating directly with patients with an ID. Shared decision making is a priority within the NHS (Coulter et al., 2011) and the need for personalisation and self-directed care has been highlighted within Valuing People (Department of Health, 2001) and Putting People First (Department of Health, 2007). Providing an individual has the capacity, as outlined in the Mental Capacity Act 2005, they should be involved in treatment and care decisions.

This is not the only study to conclude that communication interventions would be helpful. Tuffrey-Wijne et al. (2005), for example, also found that healthcare professionals, including nurses, were concerned about communicating with people with an ID and suggested that communication training tailored to patients with an ID may improve confidence, negating the need for inappropriately high reliance on caregiver involvement. It is, therefore, of concern that there is a move away from inclusion of advanced communication skills training as a component of peer review measures for oncology in the UK; this may mean that many oncology professionals will continue to have little or no knowledge of effective communication strategies for patients with complex communication needs. Our findings indicate that such training is essential. Further research into the specific communication barriers and anxieties held by oncology nurses, for example time constraints, is warranted (Hemsley et al., 2012) and may lead to more effective communication interventions: only by overcoming these communication difficulties can best practice care be achieved for all patients, including those with an ID.

Study evaluation

Recruiting through a national society should have made it possible to reach a wide group of participants. However, response rates were lower than anticipated and as a proportion of registered

UKONS members our sample is small. Our recruitment method is most likely responsible for this low recruitment rate: online survey research, especially that which uses an unanticipated email request, often results in lower than expected response rates (Fan and Yan, 2010). Nonetheless, the sample was broadly representative, thus indicating that the results may still be generalizable throughout the UK. Replication work in large samples, including those outside of the UK would be beneficial, to lend further support to these novel findings.

Conducting research into perceptions and attitudes can be difficult, not least because it is difficult to obtain frank and honest answers regarding sensitive subjects; vignette methodology enables researchers to explore such areas, as it is less direct than being asked about personal experiences (Braun and Clarke, 2013). When measuring perceptions of care, participants are usually required to have some experience of working with the population in question. By using vignette methodology, participants were able to express their care perceptions regardless of their previous experience; thus, we were able to access a wider sample and could compare the perceptions of participants who had previous experience of working with patients with an ID, and those who did not. Whilst this methodology has been beneficial to explore the care perceptions of oncology nurses with and without experience, it would be valuable to establish actual experiences of oncology nurses who have cared for this patient group, including complications they faced and how they resolved them; a qualitative methodology would be the most advantageous study design.

Conclusions

This research has taken a novel approach to investigate the care perceptions of oncology nurses, a notable and important gap in the current oncology nursing literature. It is evident from our data that providing cancer care to patients with an ID is perceived as being more difficult in many respects, however previous experience and increased knowledge working with this specific patient group acts as a protective factor against negative effects. Interventions to increase ID awareness and knowledge should be implemented to reduce anxiety and improve the perceptions and attitudes of oncology nurses when caring for this group of patients.

Conflicts of interest

None.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.ejon.2015.03.002>.

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