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7 **Accepted Manuscript:**
8 **Caring for cancer**
9 **patients with an**
10 **intellectual disability:**
11 **Attitudes and care**
12 **perceptions of UK**
13 **oncology nurses**
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25

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

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42 **Abstract**

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

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

50 **Results:** Participants felt less comfortable communicating with patients with an ID about their illness
51 ($F(1,82) = 59.52, p < 0.001$), more reliant on a caregiver for communication ($F(1,82) = 26.29, p <$
52 0.001), and less confident that the patient's needs would be identified ($F(1,82) = 42.03, p < 0.001$) and
53 met ($F(1,81) = 62.90, p < 0.001$). Participants also believed that caring for this patient group would
54 induce more stress, compared with patients without an ID ($F(1,81) = 31.592, p < 0.001$). Previous
55 experience working with ID patient groups appears to mitigate some perceptions about providing care
56 to this population.

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

60

61 **Keywords:** Oncology nurses, intellectual disabilities, cancer, stress, knowledge, communication

62 **Introduction**

63 Providing nursing care for cancer patients can be emotionally demanding (Emold et al.,
64 2011). Nurses are at an elevated risk of stress, job dissatisfaction and burnout, heightened by
65 perceived staff shortages (Toh et al., 2012). Caring for individuals with an intellectual disability (ID)
66 can also be particularly challenging for healthcare professionals (Mutkins et al., 2011; Skirrow and
67 Hatton, 2007) with high potential for stress and burnout (Lin & Lin, 2013); and is associated with
68 incidents of challenging behaviour (Hensel et al., 2012; Mills & Rose, 2011) and perceived role
69 conflict or ambiguity (Vassos & Nankervis, 2012). Over time, more people with an ID are being
70 diagnosed with cancer, in part due to increased life expectancy (Hanna et al., 2011); thus oncology
71 nurses, among other healthcare professionals, are supporting more patients with additional needs and
72 communication challenges. Given that caregiver stress is prevalent for cancer and ID professionals, it
73 stands to reason that additional difficulties will arise when providing care for a cancer patient with an
74 ID.

75 Successful communication is vital when caring for cancer patients (Arora, 2003; Kissane et
76 al., 2012); however research demonstrates that when caring for a patient with complex
77 communication needs, nurses find their ability inhibited by time constraints (Hemsley et al., 2012).
78 Discussions about consequences of cancer treatment may include intimate care concerns; Turk et al.
79 (2012a) report discomfort for both the interviewer and interviewee (with an ID) when discussing such
80 issues. Communication difficulties may, therefore, lead some healthcare professionals to
81 communicate with a caregiver rather than the patient directly (Gibbs et al., 2008; Ryan et al., 2011);
82 although, this information is not always accurate and congruent with information otherwise provided
83 by the patient (Turk et al., 2012b), potentially leading to misinformation and miscommunication.

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

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

97

98 **Method**

99 ***Participants***

100 Participants were nurses working in oncology or a related field (i.e. palliative care), and were
101 members of the UK Oncology Nursing Society (UKONS). All 2,309 UKONS members were invited
102 to participate; 138 people responded, with 83 participants (Table 1) fully completing the
103 questionnaires.

104

105 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	

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)
Missing data	2 (2.4)
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

106

107 **Materials**

108 *Vignettes*

109 Using vignettes, particularly when exploring stigma (e.g. Scior, 2011), is a common and
110 effective approach which allows researchers to gauge, with relative accuracy, the perceptions and
111 beliefs of a participant group regarding a specific situation (Braun & Clarke, 2013); and has
112 applications to healthcare provision and nursing (e.g. Wandner et al., 2014). Vignette studies are

113 of particular use within potentially sensitive research; less direct than traditional questionnaires, the
114 participant is encouraged to construct a realistic reaction to a hypothetical situation (Braun & Clarke,
115 2013).

116 The vignettes and accompanying care perception questions were devised by the researchers.
117 Four vignettes described patients, with two slightly different versions of each; additional information
118 was included in one version of each vignette, indicating that the patient had an ID (Box 1). Vignettes
119 were randomly assigned to participants; with each participant receiving four different vignettes (two
120 ID and two non-ID); for instance, if vignettes A and D described a patient with an ID, the patient in
121 vignettes B and C would not have an ID.

122 Following each vignette participants answered twelve questions, measuring care perceptions
123 and attitudes (detailed in Table 2); responses were measured on a 5-point Likert scale, ranging from
124 “1 - Strongly disagree” to “5 - Strongly agree”. Participants were then asked to consider generally
125 providing care to a patient with an ID and to answer two open-ended questions: “If you were unsure
126 about how to provide the highest quality care for this patient, would you know where to go to for
127 advice? Where would that be?” and “Are there any additional training needs you believe would be
128 beneficial to help provide care to this person?”

129

130 *Perceived Stress Scale*

131 Developed by Cohen et al. (1983), the Perceived Stress Scale (PSS) is a 10-item self-report
132 measure. Items include: “In the last month, how often have you felt nervous and “stressed”?” and are
133 scored on a 5-point Likert scale (“0 - Never” to “4 - Very Often”). Four positive questions are reverse
134 scored, and the responses totalled; a high score indicates a high level of perceived stress. Within this
135 study, the PSS has high reliability ($\alpha = 0.84$); consistent with other research ($\alpha = 0.82$; Andreou et al.,
136 2011).

137

138

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.

139

140 Box 1. Example vignettes

141

142 ***Procedure***

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

149

150 ***Analysis***

151 Each participant's scores for all twelve questions regarding their care perceptions for both
152 viewed ID vignettes were totalled, and a mean score was calculated; total and mean scores were also
153 calculated for the questions regarding the non-ID vignettes. A series of two-way within-participants
154 ANOVAs tested the main effects of vignette type (ID or non-ID) on participant's care perceptions.
155 Exploratory analysis to discover any interaction effects with other variables (e.g. previous experience
156 of ID patient groups) was undertaken using 2 x 2 mixed measures ANOVAs.

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

160

161 **Results**

162 ***Care perceptions***

163 Significant main effects of vignette type (ID or non-ID) were found for all twelve questions
164 measuring care perceptions (Table 2); indicating that participants felt more confident in their
165 knowledge, training and experience, better able to identify and meet the needs, and communicate with
166 patients without an ID. Participants held more positive perceptions about patients without an ID and
167 felt that caring for a patient with an ID would cause them to feel more stressed. Most differences
168 between ID and non-ID care perception questions had a large or medium effect size (Cohen, 1988),
169 indicating that the means for these care perceptions were substantially different. The difference in

170 responses to one care perception (understanding the patient's circumstances) had a small effect size (d
171 = -0.46); thus the difference in means was marginal.

172

173 *Interaction effects*

174 Significant interaction effects were discovered whereby participants who had previous ID
175 experience felt that they possessed more relevant knowledge ($F(1,81) = 7.670, p = 0.007$) and
176 experience ($F(1,81) = 6.992, p = 0.01$) when providing care for a patient with an ID than participants
177 with no experience. These participants were also more confident in meeting the needs of patients with
178 an ID ($F(1,80) = 4.314, p = 0.041$) and felt more positively about providing care ($F(1,80) = 11.458, p$
179 = 0.001). Participants with previous experience felt more confident in providing appropriate care for
180 patients with an ID ($F(1,79) = 6.663, p = 0.012$) and believed that they would become less stressed
181 when providing this care than participants with no previous experience ($F(1,80) = 6.263, p = 0.014$).

182 Participants with no previous ID experience felt that they had received more sufficient
183 training to care for a patient without an ID than with an ID, this difference for participants with
184 previous experience was less evident ($F(1,81) = 6.381, p = 0.013$). Additionally, participants with no
185 prior experience felt that they were better able to understand the circumstances of patients without an
186 ID; this difference was less prominent for participants with previous ID experience ($F(1,80) = 4.928,$
187 $p = 0.029$).

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

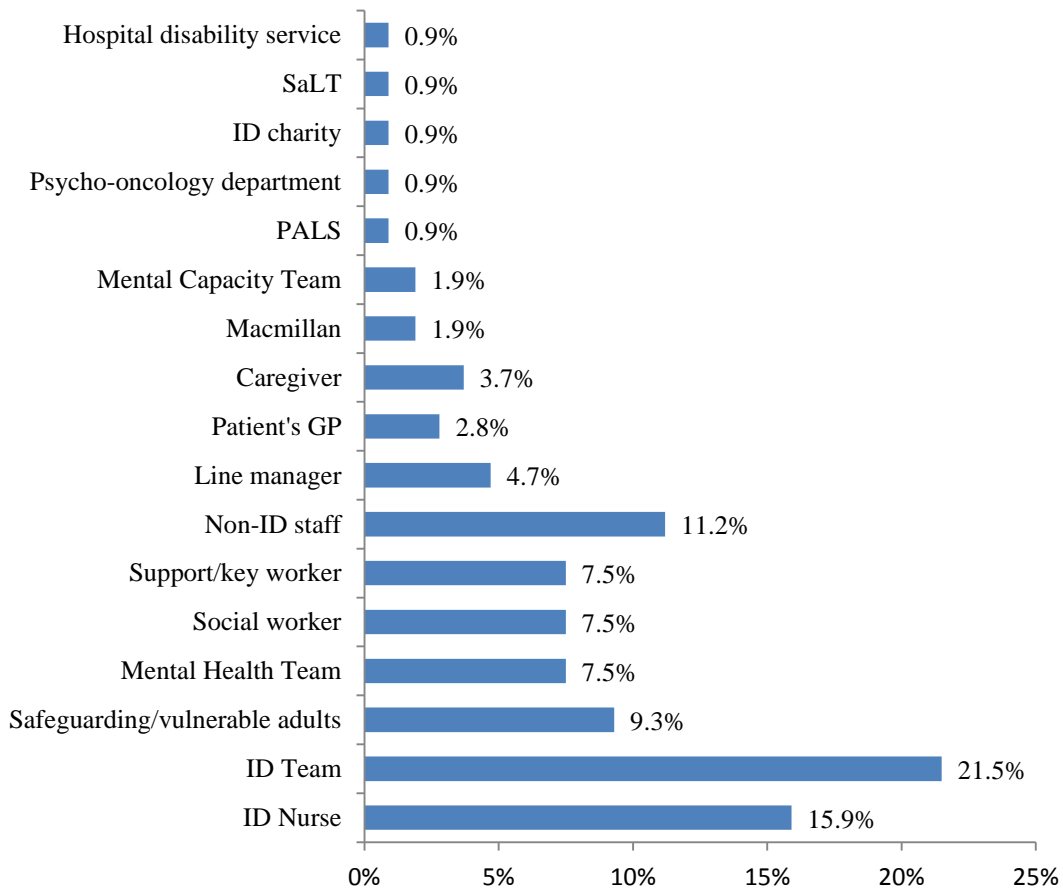
Care Perception Question	ID vignettes	Non-ID vignettes	Difference	Effect size
			between ID and non-ID (<i>F</i>)	(Cohen's <i>d</i>)
I believe that I have the sufficient level of knowledge to provide care for this patient.	3.69 (.78)	4.20 (.59)	(1,82) 36.80*	-0.74
I believe that my previous nursing experience will assist me in providing care for this patient.	3.92 (.74)	4.42 (.46)	(1,82) 41.25*	-0.81
I believe that I have received sufficient training to provide the highest quality care to this patient.	3.34 (.94)	3.86 (.82)	(1,82) 42.76*	-0.59
I believe that I would be able to successfully communicate with this patient.	3.74 (.60)	4.33 (.52)	(1,82) 60.50*	-1.05
I feel comfortable talking to this patient about their illness.	3.79 (.70)	4.37 (.54)	(1, 82) 59.52*	-0.93
I would be dependent on the person accompanying the patient to	2.70 (.84)	2.16 (.87)	(1,82) 26.29*	0.63

communicate with the patient.

I feel confident that the needs of this patient would be identified.	3.43 (.74)	3.98 (.60)	(1,82) 42.03*	-0.82
I feel confident that the needs of this patient would be met.	3.38 (.69)	3.92 (.58)	(1,81) 62.9*	-0.85
I understand this patient's circumstance.	3.37 (.88)	3.79 (.93)	(1,81) 28.17*	-0.46
I feel positively about providing this patient with care.	3.85 (.64)	4.27 (.57)	(1,81) 39.54*	-0.69
I feel confident that I would be able to provide this patient with the appropriate care.	3.77 (.64)	4.22 (.58)	(1,80) 37.81*	-0.74
I believe that providing care for this patient would cause me to become stressed.	2.71 (.89)	2.26 (.88)	(1,81) 31.59*	0.51

196 **Seeking advice and training needs**

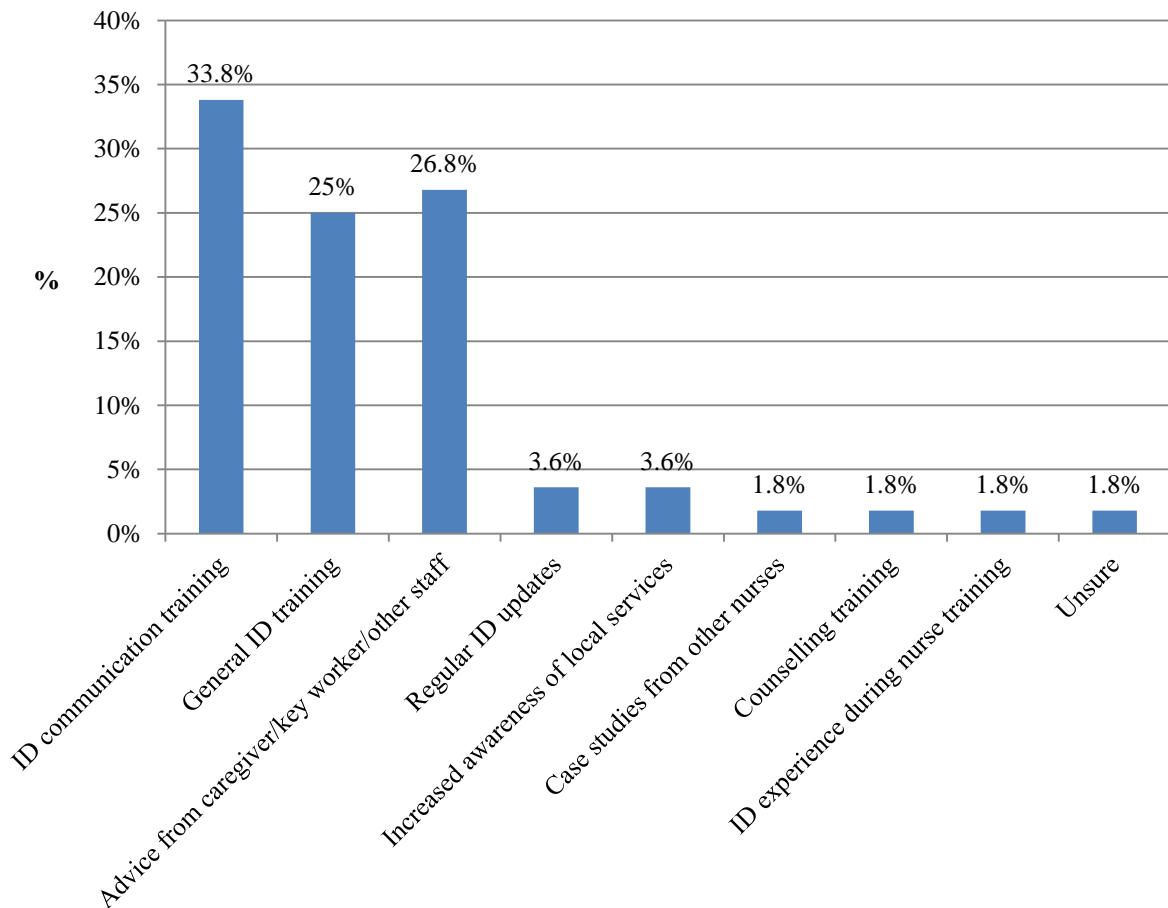
197 **Seeking advice.** Of 78 participants to answer this question, 64 participants made 107
198 suggestions regarding where they would seek advice when caring for a patient with an ID; these were
199 coded into wider categories. One participant stated that the specific circumstances and needs of the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



201
202 Figure 1. Participant identified sources of advice when caring for a patient with an ID

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

205



206

207 Figure 2. Participant identified additional training needs for caring for patients with an ID

208 **Discussion**

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

215

216 ***Care perceptions***

217 As hypothesised, oncology nurses felt less positive and confident about providing care to
 218 patients with an ID, including reporting having less relevant knowledge, training and experience for
 219 caring for this patient group. Similar results have been reported in other populations, for instance

220 palliative care professionals often lack confidence in supporting people with an ID (McIlfatrick et al.,
221 2011; Stein, 2008), and are unaware of best practices (Ryan et al., 2011). Cancer patients will often
222 have high expectations of oncology nurses (Sapir et al., 2000) thus, it is imperative that they
223 understand how to meet the needs of all patient groups, or be able to access training to facilitate their
224 understanding. Our study provides valuable insight into the confidence levels of oncology nurses, and
225 suggests that this is lacking when considering the care of patients with an ID.

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

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

247 Stress and burnout for both cancer and ID professionals is relatively high (Emold et al., 2011;
248 Mutkins et al., 2011), thus it is unsurprising that our participants felt that they would be additionally
249 burdened by a cancer patient with an ID. The perceived shortage of knowledge, experience and
250 confidence when caring for this patient group may well have contributed to this perception. This is
251 supported by the wider literature, whereby it was reported that accident and emergency nurses felt that
252 they lacked knowledge when caring for patients with an ID, which led to them being fearful of
253 communication and care provision to this patient group (Sowney & Barr, 2006). It is evident that
254 emotions related to supporting a cancer patient with an ID are complex; further exploration should
255 aim to facilitate a broader understanding of the emotional impact of providing care to this population
256 (including feelings of stress) on oncology nurses, among other oncology professionals.

257

258 *Previous experience and training needs*

259 Participants with previous experience of working with people with ID felt more positively
260 about meeting the patient's needs, providing appropriate care, and feeling additional stress when
261 providing care to this patient group, than did participants with no such prior experience. Previous
262 research has found that increased familiarity and understanding of people with an ID can reduce
263 anxiety when providing care (Li et al., 2012); and a recent literature review (Ryan & Scior, 2014) of
264 24 studies, in which interventions aimed to improve medical students' attitudes towards patients with
265 an ID, found that most studies had positive effects. Ryan and Scior noted that findings were not
266 unanimous across all studies, and that some interventions were methodologically limited (e.g. they did
267 not employ stringent measures and control groups were often absent), which should be noted for
268 future research. However, given that these interventions were effective in a group who had no prior
269 experience of working with ID populations, similar work exploring their efficacy in oncology nurses
270 would be a valuable addition to the literature. This may not only improve care perceptions, but also
271 decrease the associated anxiety, uncertainty and perceived burden when caring for this population.
272 Future studies should attempt to discover the most effective form of training to improve nurses'
273 attitudes and care perceptions (e.g. educational, practical, or a combined approach) as the results may
274 potentially benefit not only the patient, but also the wellbeing of carers and healthcare professionals.

275 Most participants in our study reported that they would seek advice from another professional
276 (e.g. ID team, ID charity, additional needs professional, line manager) to supplement their own
277 experience and knowledge, this has the added benefit of providing peer-support within the workplace.
278 Multi-disciplinary team (MDT) working is common within both cancer (Rajan et al., 2013) and ID
279 (Balogh et al., 2008) care, but communication between ID and some oncology specialist teams (e.g.
280 palliative care) has been previously reported to be problematic (Ryan et al., 2010). Having a strong
281 network of managers and support from other staff is beneficial to overall emotional and practical
282 functioning (Aycock & Boyle, 2009; Davis et al., 2013) and may be especially helpful when caring
283 for populations with additional needs.

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

296 None of the participants reported that they would consult the patient themselves about how
297 best to support them, despite evidence that people with an ID value involvement in their own
298 healthcare decisions (Tuffrey-Wijne et al., 2007). This corresponds with our earlier finding that
299 participants felt less confident communicating directly with patients with an ID. Shared decision
300 making is a priority within the NHS (Coulter et al., 2011) and the need for personalisation and self-
301 directed care has been highlighted within Valuing People (Department of Health, 2001) and Putting

302 People First (Department of Health, 2007). Providing an individual has the capacity, as outlined in the
303 Mental Capacity Act 2005, they should be involved in treatment and care decisions.

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

317

318 *Study evaluation*

319 Recruiting through a national society should have made it possible to reach a wide group of
320 participants. However, response rates were lower than anticipated and as a proportion of registered
321 UKONS members our sample is small. Our recruitment method is most likely responsible for this low
322 recruitment rate: online survey research, especially that which uses an unanticipated email request,
323 often results in lower than expected response rates (Fan & Yan, 2010). Nonetheless, the sample was
324 broadly representative, thus indicating that the results may still be generalizable throughout the UK.
325 Replication work in large samples, including those outside of the UK would be beneficial, to lend
326 further support to these novel findings.

327 Conducting research into perceptions and attitudes can be difficult, not least because it is
328 difficult to obtain frank and honest answers regarding sensitive subjects; vignette methodology
329 enables researchers to explore such areas, as it is less direct than being asked about personal

330 experiences (Braun and Clarke, 2013). When measuring perceptions of care, participants are usually
331 required to have some experience of working with the population in question. By using vignette
332 methodology, participants were able to express their care perceptions regardless of their previous
333 experience; thus, we were able to access a wider sample and could compare the perceptions of
334 participants who had previous experience of working with patients with an ID, and those who did not.
335 Whilst this methodology has been beneficial to explore the care perceptions of oncology nurses with
336 and without experience, it would be valuable to establish actual experiences of oncology nurses who
337 have cared for this patient group, including complications they faced and how they resolved them; a
338 qualitative methodology would be the most advantageous study design.

339

340 ***Conclusions***

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

348

349 **Acknowledgements**

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351 study to its members.

352

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