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“A tool doesn’t add anything”: The importance of added value: use of observational pain tools with patients with advanced dementia approaching the end of life - a qualitative study of physician and nurse experiences and perspectives

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1 **“A tool doesn’t add anything”. The importance of added value: use of observational pain**
2 **tools with patients with advanced dementia approaching the end of life - a qualitative**
3 **study of physician and nurse experiences and perspectives**

4

5 **Running title:** Pain assessment in advanced dementia

6

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55 **Abstract**

56 **Background:** Observational Pain Tools (OPTs) are widely recommended in healthcare
57 policies, clinical guidelines and recommendations for pain assessment and management.
58 However, it is unclear whether and how these tools are used for patients with advanced
59 dementia approaching the end of life. **Aim:** To explore hospice, secondary and primary care
60 physicians' and nurses' use of OPTs with patients dying with advanced dementia and their
61 perspectives on practice development and training needs. **Methods:** Twenty-three physicians
62 and 24 nurses with experience of caring for people dying with advanced dementia were
63 recruited from primary care surgeries (n=5), hospitals (n=6), hospices (n=4) and nursing homes
64 (n=10). Semi-structured, face-to-face interviews were conducted. Interviews were digitally
65 recorded, transcribed verbatim and thematic analysis applied to identify core themes. **Results:**
66 Three key themes emerged: (1) use of OPTs in this vulnerable patient population; (2) barriers
67 to the use of OPTs and lack of perceived 'added value' and (3) perspectives on practice

68 development and training in pain assessment in advanced dementia at end of life. Just over
69 one-quarter of participants (n=13) routinely used OPTs. Reasons for non-use included
70 perceived limitations of such tools, difficulties with their use and integration with existing
71 practice and lack of perceived 'added value'. Most participants strongly emphasised a need for
72 ongoing training and development which facilitated transfer of knowledge and
73 multidisciplinary skills across professions and specialties. **Conclusions:** Health professionals
74 require ongoing support in developing and integrating change to existing pain assessment
75 protocols and approaches. These findings have important implications for health education,
76 practice and policy.

77 250 words

78

79 **Keywords:** Dementia; Pain; Pain Measurement; Pain Assessment; Palliative Care; Education,
80 Medical; Nursing; Physicians; Nurses

81

82 **Key-points**

83

84 • Barriers to implementing and integrating use of standardised observational pain tools for
85 people dying with advanced dementia include difficulties experienced with using the tools
86 themselves, uncertainty arising from the limitations of tools and perceived lack of value in
87 using them.

88

89 • Lack of guidance in health policies and recommendations as to how these tools might be
90 effectively integrated with existing approaches resulted in lack of adoption of
91 recommendations and strengthened commitment to existing practice.

92

- 93 • Healthcare professionals emphasised a need for increased investment in ongoing, needs-
94 driven, clinician-led training and development in pain assessment and management in
95 dementia.

96

97 **Introduction**

98 Pain is common in people with advanced dementia approaching end of life, causing significant
99 concern for healthcare professionals (HCPs) responsible for its assessment and management.¹⁻

100 ³ Untreated pain has serious implications for quality of life and is associated with onset or
101 exacerbation of depression, delirium, sleep disturbance, cognitive decline and ‘sundown
102 syndrome’ (neuropsychiatric symptoms including confusion, aggression or anxiety in the
103 afternoon, evening and at night).^{4,5} Increasing evidence supports an association between pain
104 and behavioural and psychological symptoms of dementia.⁶⁻⁹ Pain assessment and management
105 form cornerstones of palliative care for people dying with dementia but are challenging for
106 patients unable to reliably self-report due to cognitive deterioration.¹⁻³ Previous studies have
107 reported under-recognition and potentially inappropriate treatment of pain among people with
108 dementia particularly in nursing home settings.¹⁰⁻¹³

109

110 Increasing research focus on pain assessment in dementia has led to the development of
111 numerous observational pain tools (OPTs), which require observation of patients for several
112 behavioural and nonverbal indicators of pain and calculation of an aggregated score to indicate
113 estimated pain intensity (mild, moderate, severe).^{14,15} Although use of OPTs is supported as
114 part of best practice care for people living and dying with dementia, there is ongoing debate
115 regarding their validity, reliability and clinical utility in practice.¹⁵⁻²¹ Much of this stems from
116 wide variation in methods, participants, disease severity and settings in which these tools were

117 developed, and the paucity of studies which have robustly and systematically trialled, evaluated
118 and reported on their impact on patient outcomes.¹⁵ Additionally, many of the behavioural and
119 nonverbal cues that indicate pain also present in expressions of non-pain related distress; there
120 is no clear indication in the research literature as to whether OPTs are able to distinguish
121 between pain and distress or whether they may detect both.²²⁻²⁴ HCPs experience several
122 challenges with use of OPTs in practice. These include differentiating pain from distress,
123 insufficient training and support for conducting pain assessments with severely cognitively
124 impaired patients unable to self-report, misguided perceptions regarding pain experiences and
125 neural processing in people with dementia, and workload and other organisational/institutional
126 pressures which restrict time available to conduct and interpret pain assessments.^{6,25-30}

127

128 Despite these challenges, health policies, clinical recommendations and guidelines widely
129 recommend use of OPTs when assessing pain in people with dementia and many private health
130 providers mandate their use as part of pain assessment protocols.¹⁶⁻¹⁸ However, exploration of
131 whether, to what extent and how HCPs integrate and apply these tools in clinical practice is
132 lacking in the current literature.

133

134 This study aimed to explore hospice, secondary and primary care physicians' and nurses' use
135 of OPTs with patients dying with advanced dementia and their perspectives on practice
136 development and training needs in this area.

137

138 **Methods**

139 *Sample and setting*

140 Criterion purposive sampling was used to recruit a maximum variation sample of physicians
141 (n=23) and nurses (n=24) from general practice surgeries (n=5), hospitals (n=6), hospices (n=4)

142 and nursing homes (n=10). The following inclusion criterion was applied: experience of caring
143 for people in the advanced stages of dementia who were approaching the end of life or who
144 had since died. Participants were recruited from care settings geographically dispersed across
145 a region of the United Kingdom (Northern Ireland [NI]).

146

147 *Recruitment*

148 Index contacts (Hospice Medical Directors [n=4], secondary care consultant physicians [n=4],
149 General Practitioners [GPs; n=7] and nursing home managers [n=16]) with experience caring
150 for people with advanced dementia approaching the end of life disseminated study information
151 to eligible staff and identified other suitable organisations to approach for participation. Study
152 information included a cover letter (outlining aims and objectives and inviting participation),
153 participant information sheet, contact consent form and a return-address, postage paid
154 envelope. All individuals who returned a contact consent form were contacted by the research
155 fellow (BDWJ) by telephone and provided with a verbal summary of study aims and objectives.
156 Interviews were arranged for those interested in participation. Recruitment ceased when no
157 further novel data were identified and data saturation was achieved.

158

159 *Data collection and analysis*

160 Data were collected via semi-structured, face-to-face interviews conducted in participants'
161 place of work between June 2014 and September 2015. An interview guide was used (Table
162 1); questions were derived from literature review, consideration of gaps in current knowledge,
163 and the study aims and objectives. These were refined through an iterative process of
164 discussion with the Project Management Group (PMG) comprising clinicians in
165 geriatrics/dementia and palliative care, academics specialising in palliative care, nursing and
166 pharmacy, General Practitioners (GPs) with a special interest in older adults, dementia and

167 palliative care, and one patient and public involvement representative. Prior to interview,
168 participants were provided with a verbal summary of the project aims, a statement regarding
169 data protection and participant anonymity, and an opportunity to ask questions or raise
170 concerns. Participants provided written informed consent.

171

172 Interviews were conducted, digitally audio-recorded and transcribed verbatim by BDWJ, a
173 female postdoctoral researcher with training and previous experience in qualitative research
174 methods as part of her postgraduate studies. Participants were aware that the researcher was
175 undertaking this study as part of a funded programme of work in the School of Pharmacy,
176 Queen's University Belfast, and some participants had knowledge of BDWJ due to her
177 previous postgraduate research activities.

178

179 A selection of transcripts were checked for accuracy against digital recordings by KB and HB.
180 Thematic analysis, using Braun and Clarke's (1996) paradigm, was applied to identify core
181 themes, and NVivo 10.0 software (QSR International [UK] Ltd, Cheshire, UK) facilitated
182 storage and organisation of data during analysis.³¹ BDWJ completed analysis of the full data
183 set; a selection of data was also independently analysed by KB and CP and compared with this
184 analysis. Core themes were then discussed and agreed.

185

186 *Ethics and governance*

187 Ethical approval was granted by the Office for Research Ethics Committees Northern Ireland
188 (ORECNI) [(14/NI/0013)]. Health and Social Care Trust governance permissions were granted
189 and the research protocol and supporting documentation were reviewed and approved by
190 participating hospice ethics committees.

191

192 **Results**

193 *Demographics*

194 Forty-seven HCPs (23 physicians and 24 nurses) participated in the study. Physicians' average
195 length of clinical experience was 17.5 years (range: 5 years to 31 years); nurses had on average
196 13.8 years of clinical experience (range: 3 months to 34 years). A full profile of participant
197 characteristics is available in Table 2. Average interview duration was 18 minutes for
198 physicians and 37.9 minutes for nurses.

199

200 *Key themes*

201 Three core themes were identified: (1) use of OPTs in advanced dementia towards the end of
202 life; (2) barriers to the use of OPTs and the importance of 'added value' and (3) perspectives
203 on practice development and training in pain assessment in advanced dementia in end of life
204 care.

205

206 *Use of OPTs in advanced dementia towards the end of life*

207 Pain assessment protocols in all care settings from which participants were recruited mandated
208 or recommended use of OPTs for people with dementia (at all stages). However, only 13
209 (27.6%) participants (nurses n=11; physicians n=2) used these tools with patients in advanced
210 stages approaching the end of life. The most commonly used tool was the Abbey Pain Scale
211 (36) (n=12; 92%); one participant used an in-house purpose-designed pain assessment
212 protocol. Within this group, attitudes varied regarding use and efficacy of these tools. Five
213 participants (two hospice nurses, two nursing home nurses and one secondary care physician)
214 reported that appropriate use, in accordance with instructions and as part of wider pain
215 protocols, resulted in more prompt recognition of pain, revealed patients' patterns of presenting

216 pain, provided estimation of pain severity, facilitated monitoring of treatment response and
217 enabled continuity of pain assessment and management across changing staff shifts (Table 3).
218 Use of OPTs facilitated pain reporting and communication within and across teams and
219 specialties; secondary care participants believed that pain scores, as clinical measures, were
220 more universally understood across specialties than qualitative descriptions (Table 3). Nursing
221 home nurses believed that standardised assessments improved pain reporting to GPs and
222 reported that OPTs were useful in helping less experienced staff recognise pain (Table 3).

223

224 Most participants in this group (n=8) reported using OPTs to comply with care provider or
225 local trust protocols, but questioned their efficacy and reliability for patients dying with
226 advanced dementia. Many believed that the OPT mandated or recommended for use (in these
227 cases, the Abbey Pain Scale³²) did not seem appropriate for use for these patients. Most
228 reported difficulty observing behavioural and nonverbal cues in patients with flat affect, those
229 who fluctuated in consciousness and those exhibiting conservative responses to pain.
230 Uncertainty as to whether behavioural and nonverbal cues observed were pain-related or
231 indicators of non-pain related distress or behavioural and psychological symptoms of dementia
232 was widely reported (Table 3). Most expressed a belief that pain scores lacked clinical meaning
233 in the absence of other contextual and collateral knowledge about the patient. All eight
234 participants reported that they did not document pain scores nor were they considered in
235 treatment decisions (Table 3).

236

237 *Barriers to the use of OPTs and the importance of 'added value'*

238 Most participants (n=34; 72%), of which physicians formed the majority (n=21; 61.76%), did
239 not use OPTs with patients dying with advanced dementia. Beliefs and perceptions regarding
240 the limitations of such tools, in addition to difficulties implementing and integrating their

241 application with existing practices motivated decisions to forgo their use. Most participants
242 expressed strong beliefs that OPTs did not add anything of value to existing approaches (Table
243 3). Drawing from a holistic evidence base which included: patients' medical and histories;
244 recent and current symptoms; collateral psychosocial history from key care staff, allied
245 professionals and patients' families; and clinical and physical examinations; was perceived to
246 be a more thorough approach to assessment. For many, a relatively simplistic tool was not
247 considered a suitable substitute for clinical training and experience (Table 3).

248

249 In many cases, OPTs had dropped out of use due to inconsistent use and documentation of
250 tools, wide variation in pain scores for the same patient depending on which member of staff
251 conducted the assessment, and tension among staff regarding pain scoring and interpretation.
252 In some cases, experienced professionals had withdrawn their use due to staff completing
253 assessment paperwork in the absence of patient observation and review (Table 3). Use of a
254 simple tool in a clinical area widely recognised as complex was perceived to disregard HCPs'
255 years of extensive training and experience and was widely criticised (Table 3). These
256 participants also commented on the lack of sound rationale regarding the selection of a tool,
257 information regarding the positive outcomes arising from its use and guidance regarding how
258 the tool might be integrated with existing clinical practice and protocols (Table 3).

259

260 A need for considered translation of interventions from academic research to clinical practice
261 which clearly describes a process of integration and demonstrates how such interventions
262 improve current practice and/or patient outcomes was emphasised (Table 3).

263

264 *Perspectives on practice development and training in pain assessment in advanced dementia*
265 *in end of life care*

266 Most participants reported that pain recognition and diagnosis of pain type, location and
267 intensity were challenging in this patient population, making appropriate pain management
268 difficult to achieve. Most emphasised a critical need for investment in upskilling HCPs across
269 settings and specialities to appropriately and confidently manage end of life care including pain
270 and symptom management (Table 3). Ongoing training and professional development in
271 symptom assessment and management and end of life care was deemed essential. Most
272 participants strongly emphasised that such training must be needs-driven, offer a balance of
273 didactic training and patient case discussion, be focused on transferable knowledge and skills
274 rather than theory, and be clinician-led and delivered (Table 3). Experienced physicians
275 emphasised the need for robust evaluation of all training and educational interventions to
276 determine their feasibility, utility, ability to deliver educational objectives and impact on staff
277 and patient outcomes (Table 3).

278

279 **Discussion**

280 *Main findings/results of the study*

281 Although all participants in the present study appeared to be aware of health policy and
282 recommendations regarding use of OPTs with patients with dementia, only a minority were
283 routinely adopting this practice with patients dying with advanced dementia. Among these
284 individuals, there was variation in attitudes towards OPTs. A small minority had effectively
285 integrated standardised OPT use with existing practice, resulting in positive outcomes
286 including quicker recognition and understanding of pain experiences for newly admitted
287 patients, improved continuity of pain assessment and management across staff and changing
288 shifts, and improved pain reporting within and across care teams, professions, care settings and
289 specialties. Other studies have reported similar positive outcomes including improvements in

290 symptom assessment and management and overall care provision.³³ However, many
291 participants who reported using OPTs did so solely to comply with local recommendations or
292 healthcare policies, did not use the scores from these tools to inform treatment decisions and
293 in many cases, did not document scores. Doubts regarding the clinical utility of scores from
294 subjective observation as measures of pain (rather than distress or both pain and distress), and
295 difficulties using tools with patients unable or unaccustomed to express behavioural and
296 nonverbal signs of pain, resulted in uncertainty regarding OPT use. In these cases, participants
297 abandoned pain scores, relying instead on existing practices and protocols to inform treatment
298 decisions. Other studies have reported similar challenges experienced by HCPs using OPTs
299 with people with dementia.²⁵⁻²⁸

300

301 Most participants in this study did not use OPTs when assessing pain in people with advanced
302 dementia in the final month of life. Beliefs about the limitations of OPTs, difficulties
303 experienced in their application with dying patients, inconsistencies in their use and
304 documentation, staff disagreement regarding observational scores, and beliefs that the
305 outcomes of such assessment did not offer anything of ‘added value’, were key reasons for
306 non-use. Participants’ narratives revealed largely consistent approaches to pain assessment in
307 which contextual knowledge of the patient was drawn from multiple sources including medical
308 and pain histories (pain threshold, response to pain, pain coping strategies), current and recent
309 symptoms, clinical examinations, medication regimens, direct patient contact and knowledge
310 of psychosocial history provided by care staff, patients’ families and significant others (e.g.
311 clergy). This approach largely follows published practice guidelines for assessing pain in older
312 adults with dementia.³⁴ However, evidence has suggested that overreliance on personal
313 knowledge and collateral information alone may also prove an inadequate approach to pain
314 assessment if attitudes towards the patient population are negative, the patient is unknown or

315 unfamiliar to the care team or staff are inexperienced in recognising the behavioural indicators
316 of pain in people dying with dementia.³⁵⁻³⁷ Other studies have identified a need for nursing
317 home staff to receive ongoing, regular training and support in developing pain assessment
318 protocols, conducting pain assessments and responding appropriately to the outcome.³⁸⁻⁴⁰

319

320 Participants believed that health policy and other clinical directives were misdirected in
321 focusing on simple tools in a clinical area widely recognised as challenging and highly
322 complex. Failure to highlight the benefits of using OPTs and lack of guidance on how they
323 might be integrated with existing practice were other criticisms raised. This finding, although
324 arising from small proportion of participants, echoes broader key themes reported in an
325 increasing body of work examining effective translation of research interventions into clinical
326 practice.⁴¹⁻⁴⁶ This work has noted significant disparity between funding for healthcare research
327 and the number of interventions subsequently successfully integrated and implemented in
328 practice.⁴¹⁻⁴⁶ It has been suggested that successful integration and implementation requires
329 policies, directives, recommendations and other literature to reflect the values, culture, training
330 and expertise of the professionals expected to adopt a novel intervention/approach.^{47,48} A focus
331 on simplicity and the lack of knowledge and skills required to use the intervention may prove
332 counterintuitive, resulting in rejection by HCPs, particularly physicians, who pride themselves
333 on their professional knowledge, training and skills.⁴⁶⁻⁴⁸

334

335 Most participants emphasised a need for ongoing professional development and training in
336 symptom management and end of life care provision in dementia, indicating a needs-driven,
337 clinician-led approach which balanced didactic training with group discussion, skills transfer
338 and patient case discussion. Such a model, known as Project ECHO[®] (Extension for
339 Community Healthcare Outcomes), has been extensively trialled and evaluated across a range

340 of health conditions internationally.⁴⁹⁻⁵⁹ This approach, which connects a multidisciplinary
341 expert panel within specific health conditions (e.g. dementia, diabetes etc.) with HCPs from
342 multiple specialties and professions across primary, secondary, hospice and community care
343 in real time clinics using teleconferencing technology, provides a forum for mentoring and
344 skills and knowledge transfer. Previous studies have demonstrated positive outcomes of Project
345 ECHO[®] in increasing health professionals' knowledge, self-confidence and efficacy in
346 managing complex patients, improvements in patient outcomes and better integration of
347 primary and secondary care services.⁴⁹⁻⁵⁹

348

349 *Limitations of the study*

350 The findings presented here must be interpreted with caution considering the self-selecting
351 sample of participants which is likely to have drawn those with an interest in research and who
352 are open to discussing their frank opinions and perspectives. Participants were recruited
353 through index contacts, many of whom are research active; therefore, it is possible that this
354 sample of participants leans towards examples of best practice. The self-selecting nature of
355 recruitment has also drawn a concentration of professionals from general practice, hospice,
356 palliative and nursing home care; further exploration of community care and other specialties
357 in acute care is recommended as practices in these areas may vary.

358

359 *What this study adds*

360 This study revealed several key issues regarding integration and implementation of OPTs as
361 part of pain assessment protocols in primary, secondary, hospice and nursing home settings.
362 Difficulties in applying the tools in practice, lack of guidance regarding the rationale for
363 changing practice and how to integrate tools with existing protocols, along with uncertainty
364 regarding clinical validity and reliability of these tools with dying patients with advanced

365 dementia, were significant barriers to their use. Policy makers should exercise caution in
366 placing emphasis on ease and simplicity of OPT use alone, particularly in clinically challenging
367 and complex areas as this could prove counterintuitive, leading to lack of engagement with
368 OPT use. HCPs continue to report pain assessment as challenging and emphasise a need for
369 ongoing investment in training and education, which must take into consideration educational
370 needs, and balance theory with practical application of knowledge and skills.

371

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375

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603

604 **Declaration of conflicting interests**

605 Professor Peter Passmore has received funding (educational grants) from Napp, Grünenthal
606 and Pfizer, and has spoken and/or chaired meetings for these companies. Napp, Grünenthal and
607 Pfizer had no role in the development, analysis or reporting of the present study. The other
608 authors have no conflicts of interest to declare.

609

610 **Availability of data and materials**

611 The audiotaped interviews were deleted from the digital recorder following transcription, in
612 accordance with institutional data protection protocols. Transcripts are not available because
613 this would render participants identifiable

614

615 **Table 1. Interview discussion guide**

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1. Tell me about your experiences of assessing pain in patients with advanced dementia in their last few months, weeks, days and hours of life.

2. What are the likely causes of pain in people with advanced dementia in their last few months, weeks, days and hours of life?

3. Do different types of pain or different combinations of pain (e.g. breakthrough, chronic, acute, acute-on-chronic) impact on assessing whether a dying patient with dementia is in pain? If so, in what way?

4. How do you recognise/identify when a person with advanced dementia who is approaching the end of life is in pain? (Only ask if the participant doesn't cover this in the above questions)

5. Do you use pain tools to help with recognising and assessing pain?

YES

- Which one(s) do you use and why that/those one(s) in particular?
- How do you use this/these pain tool(s) in your clinical practice?
- Are the results of these pain tools recorded/documented and/or discussed with patients' family and other colleagues?
- Do the results of the pain assessment tool(s) influence the pain management strategies (i.e. the medications) that you use/prescribe? In what ways?
- What do you believe are the clinical outcomes of using these tools for managing pain in these patients?

NO

- Are there any barriers that limit the use of pain assessment tools?
- What alternative measures do you find useful in helping you assess and manage pain?
- Are there any factors that would encourage you or make it easier for you to incorporate the use of pain assessment tools in your clinical practice?

-
6. Do you think that the assessment of pain in people with advanced dementia who are nearing the end of life could be improved? In what ways?

 7. Do you think healthcare professionals require additional training/education in assessing pain in patients with advanced dementia? Who do you see delivering this type of training and how do you think it should be delivered?

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621 **Table 2. Participant demographic profile**

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		Physicians (n=23)		Nurses (n=24)		
Age		42.5	(28 years to 58 years)	36.8	(25 years to 59 years)	
Years of experience		17.5	(5 years to 31 years)	13.8	(3 months to 34 years)	
		<i>n</i>	%	<i>n</i>	%	
Gender	Male	7	30	Male	1	4
	Female	16	70	Female	23	96
Care settings	Primary Care	9	39	Nursing home	12	50
	Hospice	7	30	Hospice	6	25
	Acute Care	7	30	Acute Care	6	25
Education	None	16	70	None	17	71
	Diploma	2	9	Diploma	4	17
	Masters	4	17	Master's Degree	3	13
	PhD	1	4			

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626 Table 3. Illustrative quotes of key themes emerging from interviews with physician and nurse participants

Theme	Quote	Participant
Use of OPTs in advanced dementia towards the end of life	“[Standardised pain assessments] can be really useful because if somebody’s coming in in the last few weeks it’s for symptom control which is pain, so obviously you want to get that sorted out straightaway. We’d be starting them on the pain chart and from that there we can see where’s this pain coming from? Is it from this area, this area, this area? ‘Cause you need to know is it the same area all the time? Is it different areas?”	NURS06 Female, RGN, Hospice
	“It allows us to work interchangeably with the palliative care team because that’s what they’re used to so it means that we’re working off the same page.”	PHYS03 Male, Consultant Psychiatrist, Hospital
	“[The Abbey Pain Scale] is the one that is in use in most of the nursing homes [here]. It’s not going to give you all the answers but it can certainly give you an indication, and it’s also a recognised tool so when you’re speaking on behalf of the patient to the GP, if you’re able to say that you used this recognised tool, rather than going on and just saying “I feel that my resident is in pain”, [if] you have a recognised tool and an assessment and a score to give them, then you’ll very often find that you’ll be listened to more.”	NURS010 Female, RGN, Nursing Home
	“It is a useful tool for, for example neuro nurses who aren’t aware of if somebody [who] has dementia is sore, you know? We just take it as a given and we know what to look for in terms of facial expression or changes in behaviours but if you were new to caring for people with dementia, it is useful to say oh these are the things that I should be looking at.”	NURS015 Female, RGN, Nursing Home
	“It’s easy probably if you can see those tell-tale signs that the Abbey Pain Chart is asking you but whenever the resident is just completely unconscious you would question it. If there is another tool that we could use and compare it with, yeah why not, but I think we have been using Abbey Pain Chart for quite a while and you would question does it really work? You know? Is there something better out there that we could use?”	NURS02 Female, Nurse, Nursing Home
	“Well I would sometimes use the PAINAD, you know, the PAINAD advanced dementia tool, not as formally as counting it up but just using the facial expression and behaviour and vocalisation measurements to assess. But I wouldn’t formally put a score on it.”	PHYS04 Female, GP, Primary Care

Barriers to the use of OPTs and the importance of “added value”	“We wouldn’t routinely use a tool like that in our in-patient setting unless we were struggling because it’s kind of what we do, and we’re very tuned in to it so a tool doesn’t add anything on top of what we already know and what we’re already assessing.”	PHYS01 Female, Consultant in Palliative Medicine, Hospice
	“I’m not using any standardised pain assessments for people with dementia. It’s not the way I’ve been trained or taught in our medical school and in clinical practice. I take a history find out what they’ve been like before and then find out what they’re like now and then do a medical assessment: do they have a temperature, any evidence of infection, chest infection, kidney infections, what are they like when they’re being moved by the nursing staff, whenever they’re moved do they appear to be in pain? I do a medical assessment and then do a physical examination, you know, chest, heart, abdomen make sure they haven’t got retention of urine, and also move their arms and their legs see if there is anything obvious there.”	PHYS021 Male, GP, Primary Care
	“I would have noticed that staff were perhaps guessing that the score was going to be the same and they weren’t going back and actually looking at the resident and assessing them.”	NURS010 Female, Nurse, Nursing Home
	“I think that when one gets into such a routine that you use the skills which you’ve acquired, you don’t necessarily move to just start using a new tool.”	PHYS05 Male, Consultant Psychiatrist, Hospital
	“They’re coming in with the Abbey Pain Scale, they’re teaching how to administer it in a very quick manner but they’re not actually showing why it needs to be done and showing the uniqueness of end stage dementia and the unique challenges that that presents.”	NURS010 Female Nurse, Nursing Home
	“The issue with policies is that there are so many different problems and there are so many assessment tools now I think that the wards are kind of bombarded with that. I suppose it’s just making sure that we’re not adding to the paperwork burden too significantly and that the staff are aware of how to use those tools to work out if they patients seem sore and emphasising the best practice approach to symptom assessment and management.”	PHYS015 Male Consultant Palliative Medicine Hospice
	Perspectives on practice development and training in pain	“I think there should be a rolling programme within the Trust, I think it should be part of our mandatory training, and I think it should be for all levels of staff. I think it is a major, major gap within the Trust. I think it’s a major gap within the NHS as a whole. It is trying

assessment in advanced dementia in end of life care	to get that balance of ensuring the fact that they have dementia doesn't take away from the fact that they still need clinically treated in exactly the same way as a person who is compos mentis and doesn't have any cognitive issues. I think it [pain assessment] should be part of the induction, I think it should be mandatory training."	
	"You could have a case report like "Mr X has such and such" and then group work to try and figure out what could be the possible causes, what to look out for, how to use the tool in that case and things like that."	PHYS06 Female Psychiatrist Hospital
	"I think a key thing would be to assess does it actually change their practice or influence their practice because sometimes training is done but the benefits can be lost if they're not implemented by the person and if there's not a culture of change. There has to be a culture, staff have to be working in an environment where there's a culture of improvement and where there is attention given to that particular area."	PHY015 Male, Consultant Palliative Medicine, Hospice

627 NURS: Nurse RGN; OPT: Observational Pain Tool; PHY: Physician; RGN: Registered General Nurse

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