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1 **The 'Lived Experience' of palliative care patients in one acute hospital setting – a qualitative study**

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27 **Abstract**

28 **Background**

29 There is limited understanding of the 'lived experience' of palliative care patient within the acute
30 care setting. Failing to engage with and understand the views of patients and those close to them,
31 has fundamental consequences for future health delivery. Understanding 'patient experience' can
32 enable care providers to ensure services are responsive and adaptive to individual patient need.

33

34 **Methods**

35 The aim of this study was to explore the 'lived experience' of a group of patients with palliative care
36 needs who had recently been in-patients in one acute hospital trust in the north-west of England.
37 Qualitative research using narrative interviews was undertaken, and data was analysed using
38 thematic analysis. A sample of 20 consecutive patients complying with the inclusion/exclusion
39 criteria were recruited and interviewed.

40

41 **Results**

42 Patient Sample:

43 Of the 20 patients recruited, there was a fairly equal gender split; all had a cancer diagnosis and the
44 majority were white British, with an age range of 43-87 years.

45

46 Findings from Interviews:

47 Overall inpatient experience was viewed positively. Individual narratives illustrated compassionate
48 and responsive care, with the patient at the centre. Acts of compassion appeared to be expressed
49 through the 'little things' staff could do for patients, i.e., time to talk, time to care, humanity and
50 comfort measures. AHSPCT involvement resulted in perceived improvements in pain control and
51 holistic wellbeing. However, challenges were evident, particularly regarding over-stretched staff and
52 resources, and modes of communication, which seemed to impact on patient experience.

53

54 **Conclusions**

55 Listening to patients' experiences of care across the organisation provided a unique opportunity to
56 impact upon delivery of care. Further research should focus on exploring issues such as: why some
57 patients within the same organisation have a positive experience of care, while others may not; how
58 do staff attitudes and behaviours impact on the experience of care; transitions of care from hospital
59 to home, and the role of social networks.

60

61 **Key Words**

62 Patient Experience, Narrative Research , Palliative Care, Hospital, Qualitative

63

64

65 **Background**

66 'Person centred' approaches to care delivery have been promoted as a core part of service design
67 within the National Health Service (NHS) [1]. Crucially, person centred care promotes a care
68 environment that is respectful, compassionate and responsive to the needs of individuals [2]. This is
69 not a novel idea as the person centred ethos can be seen echoed in the core principles and values of
70 the NHS; "[the NHS] touches our lives at times of most basic human need, when care and
71 compassion are what matter most"[3]. Whilst this may be an attractive concept to underpin health
72 care delivery policy, the term has been criticised for being applied without clarity of definition,
73 causing subsequent discourse around the subject to be 'woolly', particularly with regard to informing
74 actual care delivery [4].

75

76 A recent high profile review of care delivery in hospitals has shown that a lack of openness and
77 compassion led, at times, to care that was "totally unacceptable and a fundamental breach of the
78 values of the NHS" [5]. Furthermore, the Neuberger review highlighted a lack of 'patient centred'
79 care and openness around decision making as barriers to good care [6]. A failure to engage
80 meaningfully with patients may result in an approach to care delivery that 'does to' rather than
81 'works with' patients; privileging the perspective of healthcare professionals and clinically focused
82 outcomes [7]. Indeed, a lack of compassion from health care providers has been cited as a major
83 reason for dissatisfaction with the care that patients receive [8].

84

85 Failing to engage with and understand the views of patients and those close to them, has
86 fundamental consequences for future health delivery. Both government policy/guidance and the
87 research literature continues to emphasise the importance of exploring the 'patient experience' in
88 order to support service providers to provide care that is responsive and adaptive to individual
89 patient need – ie person centred [2, 9,10,11,12]. By actively seeking the views of patients and
90 families, the potential to ensure that these views are placed at the centre of service provision is

91 enhanced. This perspective sits in accordance with the overarching values of the NHS Constitution
92 [3] as well as National Guidance for End of Life Care [10,12,13]; therefore engaging service users
93 should form part of ongoing service improvement strategies.

94

95 Predominantly however, assessing the 'user experience' has centred on measuring 'satisfaction',
96 with a focus on comparison and monitoring. Some commentators suggest that current widely used
97 approaches for measuring 'satisfaction' may not be sufficiently grounded in the values or
98 experiences of patients, thus raising serious questions about the validity of the concept as a way of
99 eliciting what is important to patients and the care they receive [14,15]. In recent years assessment
100 of the performance of healthcare organisations has begun to move beyond examining clinical care
101 alone, to considering and embracing 'patient experience' as an important indicator of quality [9].

102

103 So how can we best uncover the views of patients who receive care in our NHS organisations, to
104 better understand how well it meets their needs? Patient experience is complex and multifaceted,
105 and requires more in depth methods to explore how patients and families experience the care they
106 receive[9]. Taking time to actively engage patients to find out what is really important to them has
107 the potential to unlock a richness of information not possible solely through 'satisfaction'
108 questionnaires alone[16].

109

110 Much of the recent focus of both the media and the academic literature has been on the perceived
111 deficits in care delivery for hospital in-patients nearing the end of life and their relatives and carers
112 [6,7]. We therefore chose to focus this study on a group of hospital in-patients who had life limiting
113 illness and who were potentially nearing the end of life. In order to identify a suitable group of
114 patients, we focused on inpatients who had received input during their stay from members of the
115 Academic Hospital Specialist Palliative Care Team (AHSPCT) in one acute hospital trust in the North-
116 West of England. The AHSPCT is an advisory service which takes referrals from across the hospital for

117 patients with identified specialist palliative care needs. The role of the service is to assess patients'
118 holistic needs in order to optimise comfort, well-being and quality of life, in the presence of
119 incurable, advancing illness. The AHSPCT is a multi-professional team, and includes doctors,
120 specialist nurses and allied health professionals.

121

122 **Methods**

123 The aim of this study was to explore the 'lived experience' of a group of patients with palliative care
124 needs who had recently been in-patients in one acute hospital trust in the north-west of England.

125

126 Exploring the lived experience required a phenomenological approach whereby participants were
127 encouraged to recount their experience, allowing issues that held most personal importance to
128 them unfold. This approach allows the researcher 'enter the patients world', promoting
129 understanding of their experience from the patients' perspective [18]. In-depth narrative interviews
130 were undertaken using a conversational approach where patients were encouraged to direct and
131 shape the discussion in accordance with their own experiences, views and particular concerns
132 [19,20], rather than responding to a pre-determined agenda.

133

134 *Procedure*

135 Identification and recruitment of patients:

136 In order to promote the potential to sample a range of experience, a consecutive sample of 20
137 patients who had been referred to the AHSPCT were recruited to take part. Recruitment was
138 coordinated by the main researcher (AB). AB, female, is a Clinical Nurse Specialist with the AHSPCT,
139 who was seconded for 1 year to undertake this research project.

140

141 During the recruitment phase, AB attended the morning 'run through' meeting within the AHSPCT
142 attended by the multi-disciplinary team, to prompt identification of patients who may be 'eligible'
143 for this study. Patients were considered 'eligible' if they met the following inclusion criteria:

- 144 • Hospital inpatient ≥ 18 years of age
- 145 • Referred to the AHSPCT and seen on at least two occasions;
- 146 • Due to be discharged from hospital.

147

148 Patients were not approached for this study if the following exclusion criteria applied:

- 149 • Hospital inpatient < 18 years of age;
- 150 • Recognised to be in the last few days or hours of life;
- 151 • Unable to provide fully informed consent to participate;
- 152 • Died prior to discharge;
- 153 • Unable to communicate in English.

154

155 *Information and Consent*

156 Potential participants were initially approached by a member of the clinical team, who informed
157 them that this study was being conducted. If the patient expressed interest, they then met with the
158 researcher (AB), who gave them a Patient Information Sheet (PIS) along with verbal information and
159 offered the opportunity for questions. If the patient was agreeable, a mutually agreed date/time and
160 place was arranged to conduct the interview following discharge from hospital. AB then checked
161 their agreement to participate prior to undertaking the interview, and a consent form was signed by
162 the participant.

163

164 *Interviews*

165 The interviews were conducted by the researcher (AB) in the patients' home following discharge.

166 The researcher began the interviews with an open question:

167

168 ‘Thinking back to x number of days ago when you came into hospital, can you tell me
169 everything that has happened’.

170

171 A topic guide of ‘prompts’ was also created to support this process. For example, prompts such as
172 ‘tell me more about’, ‘can you remember specific examples?’ and ‘how did you feel about that?’
173 were used in order to elicit more detailed responses where this did not occur more naturally from
174 the conversation. The interviews were conducted between October 2015 and September 2016.

175

176 It was important to consider issues of potential bias within the research process, for example the balance of
177 power in the relationship between patients and the researcher [21,22]. Considering this, the
178 interviews were conducted in a place where the patient felt comfortable, and the researcher kept a
179 field note diary to document thoughts and feelings in order to aid ongoing reflection. In addition a
180 distress protocol was available should the patient become distressed during the interview.

181

182 *Analysis*

183 Each interview was transcribed verbatim, and transcripts were analysed using Thematic Analysis,
184 facilitating exploration of how people ascribe meaning to their experiences in their interactions with
185 the environment [23]. The analysis process began at the interview stage, with the researcher keeping
186 a field note diary of thoughts, feelings and emotional responses to the interview process and
187 content. The process of analysis was cyclical and iterative in nature. Transcription further promoted
188 familiarisation with the data and generation of initial emerging themes. The transcripts were also
189 analysed in conjunction with the original recordings, so that the researcher became fully immersed
190 in the data [23]. Against each transcript, the main researcher (AB) made initial notes documenting
191 any observations, questions and interpretations that arose from the reading and re-reading of the
192 data. AB then coded each transcript and made an initial narrative summary of the key themes for in-

193 depth discussion with the wider team (TM and CM). TM and CM also independently analysed 5
194 transcripts (20%) to gain first-hand experience of the words of participants, giving the potential for a
195 richer interpretation. Where appropriate, consideration of relevant published literature further
196 enhanced the evolving interpretation.

197

198 **Results**

199 *Final Sample*

200 A total of 20 interviews were undertaken (see figure 1 for recruitment flow diagram) lasting between
201 15 minutes and 90 minutes, with a median time of 41 minutes.

202

203 As a result of the complex and palliative nature of the patient cohort, over half (53% n=296/560)
204 initially referred to the AHSPCT were either 'too ill' or 'dying' at the point of referral, meaning they
205 were not eligible for inclusion. However, many patients who were approached for inclusion
206 expressed interest in taking part in the study; of the 81 patients initially approached only 26 (32%)
207 expressly declined. Thirty five patients (43%) initially showed interest but were unable to be
208 recruited for the following reasons: deteriorating condition (n=11); subsequent death (n=10); family
209 'gate keeping' (n=10); and the required sample had been reached (n=4). The interviews took place
210 no longer than 10 days following discharge home; 14/20 interviews took place within 6 days of
211 discharge. Table 1 provides a summary of the demographic details of participating patients.

212

213 Table 1: Demographic Details

Total No: Participants	20
Male	11 (55%)
Female	9 (45%)
Age Range	43-87 years
Diagnosis	20 cancer (100%)
Ethnicity	19 White British (95%)

	1 Any other ethnic group (5%)
Median days - recruitment to Interview	6 days (IQR 5 – 7 days)
Median days - Interview to Date of Death (n=17*)	63 (IQR 35 – 218 days)

214 **3 patients still alive at close of data collection period*

215

216 *Findings from Interviews*

217 Four overarching themes were generated from the interview data and these are presented below.

218

219 *Making Time – Taking Time*

220

221 It was clear from the narratives that participants in this study were acutely aware of the pressures
222 on the staff that were looking after them, including the busyness of the wards, and staff shortages:

223

224 *"...sometimes they were run off their feet. They can't always come so you don't get bad
225 tempered or anything, you just have to wait and know that they will come." (Betty)*

226

227 *"they're very, very busy and they're trying to fit you in and decide what's the best thing to do
228 for you and they haven't got time to do, I wouldn't even call it value added, but to just
229 communicate to you to say, 'right Mr P, this is what we plan to do and this is why we're
230 doing it. There was none of that...because they are so busy and they haven't got time and
231 resource in place to provide that information to you" (Bill)*

232

233 Against this backdrop, the views of the participants highlighted how the mode and manner of
234 communication and information giving, including the number of HCPs involved and the level of
235 engagement, could further negatively impact their experience:

236

237 *"...I saw four different teams, you know what I mean, so you do lose track that is; who and*
238 *names (sic)...that was one of the problems I had anyway."* (Gerry)

239
240 *"That [lack of information] leaves you feeling as though...do they know any more, that they*
241 *don't want to tell me? ...or is [it] a matter that they just don't know what's going on?"* (Bill).

242
243 For some, it was perceived that it was not just busyness that meant that staff were less attentive
244 than they would have liked, but individual differences in the way different staff approached their
245 roles:

246
247 *" Well it was sort of nurses, I mean, erm there was some of them were, it's hard to say, some*
248 *of them were a lot better than others .. but there was others not so good; they would sit*
249 *round chatting and things like that when there was, you know, basically, work to be done .. I*
250 *mean you waited every night till nine o'clock to see which nurse .. was gonna come on and ..*
251 *you know if they were good nurses .. you would have no problems"* (Harry)

252
253 Understandably then, staff that went the extra mile to make time in their busy schedules and to take
254 time to treat these patients as individuals, were highly valued:

255
256 *"...it's just little things...that make a difference...they wanted to be there, they wanted to*
257 *care. You could tell that they wanted to care...and they made time for me...they just seemed*
258 *to care...to want to be there and help...they wanted to listen to what I have to say and*
259 *understand how I feel ...one particular nurse, she just said to me one night, you're not you're*
260 *normal self...do you need a hug? And I said, "Yeah, I do actually". So she gave me a hug and*
261 *you know, she hugged me for a while until I was ready to stop having a hug..."* (Tilly)

262

263 *“nurses used to sit with me, not only about the medication, but they used to sit with me and*
264 *listen to problems, about my health and what was going on and they used to sit with me for*
265 *quite a while” (P7)*

266

267 *Experiencing and Relieving Pain*

268 For some patients their in-patient stay was characterised by their experience of pain, and it was
269 often what they remembered most about being in hospital.

270

271 *“Erm, it’s like you know if someone, they had like, erm, wood and paper and everything and*
272 *they put a match to it and it went aflame, that’s the way I feel, ya know when it hits my right*
273 *leg...that’s how the pain was, and I felt like a fire had gone off inside me.” (Betty).*

274

275 Where physical pain was not dealt with in an appropriate and timely manner, this was highlighted as
276 having the potential to negatively impact the patient experience:

277

278 *“...they [nurses] gave me paracetamol thinking it would help and I just sat up in the chair, I’d*
279 *say for about three nights... they couldn’t give me anything stronger because I wasn’t written*
280 *up for it so I was sat in the chair...trying to stop the pain and just ended up sitting up all night*
281 *watching TV... just watching the clock until nine o’clock, until they came round with the*
282 *medication (Sadie)*

283

284 *“Sometimes we ask for medication and they’ll say I’ll get it for you, and you’d end up getting*
285 *it eventually when they’d come round with the trolley two hours later...” (Bob)*

286

287 When this was attended to however, the therapeutic value of this for patients made all the
288 difference. The act of attending to patients' pain relief appeared to embody compassion, care,
289 dignity, and being valued as a human being:

290

291 *"That was great, and somebody's on your side, I can remember her coming up to me,*
292 *whispers "I got you some more" [medication], oh thank God, yeah..." (Ritchie).*

293

294 Interestingly, although initial anxiety was reported by some around whether the involvement of the
295 Academic Hospital Specialist Palliative Care Team (AHSPCT) meant imminent death, it was their
296 involvement, particularly with regards to pain management, that was highlighted as having had a
297 positive impact:

298

299 *"Oh the pain relief, they [AHSPCT] were absolutely marvellous...it was like someone waving a*
300 *magic wand because after I'd seen them for a few occasions, about three times, er, I just,*
301 *the next time they came to see me, I said it was the first time that I'd slept properly in about*
302 *six weeks." (Sadie)*

303

304 *Loss of Control and Loss of Self*

305 Central to many patient stories, was the sense of 'struggle'; seeking to find sense and meaning in
306 their lives in the face of an uncertain and changing future with a life limiting illness:

307

308 *"I didn't know I was dying seven weeks ago...eight weeks ago I just had a bad back. I was*
309 *actually working and doing stuff and planning my life and wanting to get better, expecting to*
310 *get better, but now I'm dying and I'm not expecting to live, so I don't...I wanna understand*
311 *what's happening to me and I wanna understand what's the likely scenario but there's a*

312 *part of me that's terrified. I'm terrified of like being in agonising pain. I'm terrified of like*
313 *losing meself (sic) to the pain; the pain steals your personality." (Tim)*

314

315 Patients also described feeling 'labelled' by their illness, which in turn poses a challenge to their
316 sense of 'self' and 'identity':

317

318 *"Terminal, you know what I mean. Er, you do seem to feel a bit, a little bit different. " (Terry).*

319

320 Linked to this, some patients described the 'contagiousness' of cancer, and almost a sense of
321 isolation, from having the 'label' of a cancer diagnosis:

322

323 *"I suppose in the back of your mind...cancer is contagious...don't you, sounds silly doesn't it?*
324 *...I suppose that's were you, er you think it's, it's a horrible word cancer, but it means a lot of*
325 *things doesn't it?" (Charlie).*

326

327 For some the hospital environment provided a 'secure' and 'supportive' environment during this
328 time of flux, however once discharged home, patients described feeling 'alone' and less supported:

329

330 *"...when you come home you're very much left to your own devices...now I'm in need of a bit*
331 *of help and support...I feel as though I'm being provided with a poor...well not a poor*
332 *service, but a limited service" (Bill).*

333

334 *Burden versus benefit of treatment interventions*

335 From these patient stories, a picture emerged of wrestling with choices and decisions regarding
336 treatment options. This illustrates the subjective values placed on 'life'; quality of life or the battle to
337 survive at any cost.

338

339 *"I know I'm not gonna get better, and I thought, why do it, you know? Why put me through*
340 *anything that's intrusive at all? I really don't see the point; I really don't."* (Wendy).

341

342 *"...when you have a days like the last couple of days I've just felt ill...it's difficult to wanna*
343 *like, battle on...fighting the sickness is horrible...I'm not sure if I wanna go back, to go back to*
344 *radiotherapy though. I'm not sure I'd like it or trust it. I don't know how making me feel this*
345 *ill; can be doing me any favours."* (Tim).

346

347 The following patient quote illustrates the tensions that can arise when HCP and patients'
348 perceptions of the focus of care are not aligned, impacting on patient choice, autonomy and dignity
349 and shared decision making:

350

351 *"...it changes when you become terminal. I could understand [considering all treatment*
352 *interventions] before because then there is a real good case for it...once you go into the*
353 *terminal thing then it's a case of not so much...it's a case of what can...make it better for*
354 *now? And if the blood thinners was making me a lot worse so to me, my personal opinion, in*
355 *that situation was let's just stop them. It might not have been somebody else's [wish] but*
356 *nobody was actually saying...they were saying "This is what's going on" but [not asking]*
357 *"what do you want to do?"* (Terry).

358

359 The following patient account highlights that when HCP 'take on board' what the patient wants, and
360 work in partnership, this can alleviate the 'tension' and provide therapeutic benefits. This in turn
361 impacts on patient autonomy, dignity and comfort, reinforcing the importance of active listening and
362 shared decision making:

363

364 *“[I felt] Jubilant...because like I say over a year and somebody’s listened, and they’ve gone*
365 *away, they’ve sorted it all out, done what they promised they’d do you know like oh we’ll get*
366 *it sorted, and we’ve heard that so many times, and no they did exactly what they said they’d*
367 *do...that’s all I could ask that somebody would listen, and take on board what the patient*
368 *wants, as well as what the doctor’s experiences are, obviously a two-way street, but when it*
369 *comes to pain the patient knows what pain they’re in, not the doctor.” (Ritchie).*

370

371 **Discussion**

372 This study has generated important information on the way in which patients’ experience care
373 currently, providing an opportunity for the acute hospital to generate recommendations, to consider
374 how results from this study may inform future service design, education, training and resource
375 utilisations. The results of this study illustrate that overall the in-patient experience was viewed
376 positively for most patients, with accounts illustrating compassionate and responsive care.
377 Challenges were highlighted, however, with regard to over stretched staff and resources, along with
378 individual differences in the attitudes of staff, which was reported to have negatively impacted the
379 experience of care for some patients. Whilst this study was undertaken in one acute hospital, these
380 findings are likely to be of interest to all providers of in-patient care, as many of the themes and
381 issues highlighted here may also resonate with those care services.

382

383 Where care delivery was timely, responsive, well led and compassionate, however, this appeared to
384 contribute to patients feeling safe and valued as individuals rather than being ‘processed’ as
385 commodities; a view reinforced in the literature and recent policy documents [10,24,25]. In this
386 study, acts of compassion were experienced through the ‘little things’ that staff could do for patients
387 such as; making and taking the time to talk, to care and to display characteristics of humanity.
388 Indeed, one of the main components of ‘good care’ has been highlighted as feeling that ‘you matter’
389 [26]. This perspective supports the view that the smallest details of the patient experience can be

390 the most meaningful [27]. The NHS is under relentless pressure to improve efficiency and
391 throughput; however it is an imperative that the patient remains at the forefront of any
392 improvement strategy [2].

393

394 For patients' in this study, modes of communication could have both positive and negative impacts
395 on the patient experience. In particular, what information was given and how it was delivered
396 appeared to impact on patients' understanding of services involved, their condition and the overall
397 plan of care. Evidence suggests "effective communication is the core of every helping relationship,
398 and listening is the foundation of every medical and social service interaction" [28, p57]. Accounts
399 from this study reinforce that when HCP's were able to 'connect' with patients beyond the 'physical'
400 contact, this fostered a powerful sense of genuine human presence and care; effective
401 communication, engagement and active listening, should be reflected within the culture of care in
402 the organisation [29]. In recognition that 'dignity enhancing' or 'dignity preserving' care for palliative
403 care patients is vitally important, the use of interventions such as the 'dignity model' has been
404 highlighted as one way to ensure a person-centred approach in the acute hospital setting;
405 promoting patient autonomy and recognition of the person as an individual [30].

406

407 For many patients in this study, pain appeared to be a major concern throughout their in-patient
408 episode; a finding supported by previous studies [31,32,33]. Stories from this study reinforce the
409 'threat', highlighted by Pringle et al [30], that untimely and unresponsive symptom assessment and
410 control can be to patient dignity. For example patients described the seemingly all-encompassing
411 nature of pain and the very real distress this caused when it was unremitting and unresolved.
412 Specifically, some patients described 'a significant period of waiting for assessment and
413 administration' of pain medication, impacting on their sense of dignity and wellbeing. Poignantly,
414 patients described their relief when they felt that their pain was finally being attended to,

415 underlining the significance of pain control to a patient's sense of being cared for and valued as a
416 human being. The role of the AHSPCT was specifically highlighted in this regard, where
417 despite initial uncertainty and anxiety from some patients associated with their understanding of the
418 role of the AHSPCT [34,35,31] as noted in previous studies [30,31,36,37], their involvement resulted
419 in improvements in pain control and holistic wellbeing.

420

421 Throughout this study, patients' described the 'struggle' of living with a terminal illness, and the
422 effect this had on their sense of self and life as they knew it before their diagnosis. This was a very
423 important issue for patients, as their sense of 'self' had been ultimately changed, forcing them to
424 renegotiate this in the face of uncertainty: "Death forces us to give an ultimate meaning to life and
425 thereby transcend the apparent absurdity and meaninglessness of life in the face of death" [38].

426

427 Patients described feeling 'different' following their diagnosis, which echoes previous studies where
428 the 'stigma' of cancer can have a negative impact on a patients sense of self, resulting in a
429 'renegotiation' of identity within the new context of their diagnosis [39]. It has also been suggested
430 that over time the 'label' of a terminal illness can preclude 'sustaining self-images' resulting in
431 'diminished self-concept', as well as a fear of becoming a 'burden' to relatives as they readjust to the
432 'real world'[40]. This echoes with findings from this study, where for example despite the 'hustle and
433 bustle' the hospital provided a 'safe haven' during this uncertain time[41], where patients could
434 navigate and readjust within their 'renegotiation' of identity, self-worth, dignity and self-respect.

435

436 For some patients in this particular study, the distress prompted by this time of uncertainty
437 extended beyond their inpatient admission. Some patients reported feeling 'alone' following
438 discharge, indicating the potential for ongoing distress and need for additional support at this time.
439 This resonates with the idea that 'structures' that underpin everyday life (such as social networks
440 and relationships) can be 'disrupted' in light of serious chronic illness [42]. The 'chaos narrative'

441 [43,44] offers us another perspective that resonates with this study, for example the challenge of
442 loss and adjustment faced by study participants when leaving the safe confines of hospital to return
443 to the 'real world'. Reinforcing the importance that care services should not 'end' at the point of
444 discharge, ensuring that patients can be sufficiently supported.

445

446 Johnson suggests 'living with dignity' is bound up in the individual's sense of identity; through having
447 one's human value acknowledged, irrespective of circumstances, 'personhood' and 'self-worth'[45].

448 Johnson also highlights the risk to dignity at the end of life (EOL) as health deteriorates being
449 particularly concerning [45]. Therefore, as health professionals, it is crucial that we consider how we

450 respect these views in our conduct with others, ensuring that our interactions are dignity enriching

451 [45], seeing the 'person' in the patient, rather than merely their illness. This perspective is also

452 highlighted by Chochinov [46] and Johnson [47], who describe the Patient Dignity Question (PDQ) as

453 a means by which HPCs may enhance person-centred care, for people with palliative care needs in

454 an acute hospital.

455

456 *Strengths and Limitations*

457 This study provided a unique opportunity for one NHS organisation to explore what matters to

458 patients with a life limiting illness, in the context on their in-patient stay. The approach that was

459 taken, through listening to 'patient stories', reflects the traditions of hospice and palliative care, by

460 giving time and space to listen and gain a greater understanding from the patients perspective [48].

461

462 However it has been recognised that involving patients with a palliative illness in research studies

463 poses its own ethical and moral challenges. In this study for example due to the vulnerability of the

464 patient population, some were unable to be involved as they deteriorated or died prior to or after

465 discharge from hospital. Despite ethical and methodological debates regarding the 'morality' and

466 'appropriateness' of involving this cohort of patients in this type of research [49], it was evident

467 throughout recruitment, that patients had a desire to take part. Indeed there is growing evidence to
468 suggest that in fact, palliative care patients do have a desire to take part in research [50,51]. This
469 adds to growing literature, critiquing the potentially constraining ethical guidelines, prompting the
470 question of whether it is ethical to prohibit patients the chance to contribute to research [52,53].

471

472 Also of note was that the majority of interviews took place within the last two months of the
473 patient's life (17/20 had died by the end of the data collection period: October 2015 – September
474 2016). This is interesting given the reticence to involve patients in research as they are approaching
475 the end of life, due to the assumption that it is an unwelcome burden for them at this time [46]. The
476 inclusion criteria of this study however excluded patients that remained in hospital. It could be
477 argued that this approach limited participation, possibly denying the opportunity for other palliative
478 care patients to share their experiences and potentially silencing their voices. In addition, the
479 sample was homogenous in terms of ethnicity and all had cancer, therefore future studies may seek
480 to explore the views of a wider patient population, including patients that do not have a life-limiting
481 illness. Interestingly, the referral criteria for the AHSPT are not limited to patients with a cancer
482 diagnosis, yet these patients made up the total sample population for this study.

483

484 The issue of 'gatekeeping' was also important to consider, as for ten patients in this study family
485 members specifically requested that the patient not be approached. Reasons for this included
486 perceptions that the patient was too unwell, too tired, or it was 'not the right time' to be
487 approached, despite some patients agreeing to meet or have contact with the researcher. However,
488 there were examples where family 'gatekeepers' became part of the process [54], by facilitating
489 access to the patient and by their presence in the interview itself, potentially shaping the stories that
490 were being told. It is important to be mindful of these influences when undertaking this kind of
491 research.

492

493 **Conclusions**

494 Despite the acknowledged organisational pressures, these patient narratives highlight the
495 importance of concepts such as kindness, compassion and dignity; taking the time to 'care for
496 patients' rather than time to 'do to patients', taking the time to listen to what is most important and
497 taking the time to respond to the patient as an individual. When the patients' voice is heard and
498 healthcare professionals 'see the person behind the name' rather than the illness, this provides
499 opportunities for relationships to be built based on trust, confidence and mutual respect. This
500 ultimately impacts on the patients' experience of care, and their perception of self-worth and
501 identity and sense of dignity [46,47]. The palliative nature of illness reinforced the 'preciousness' of
502 time, underlining there is 'one chance to get it right' [55]. Having listened to our patients it is time to
503 learn and change; this study has provided an opportunity for the 'patient voice' to be heard and the
504 individual patient experience to be explored. Further research should focus on exploring issues such
505 as: why some patients within the same organisation have a positive experience of care, while others
506 may not; how do staff attitudes and behaviours impact on the experience of care; transitions of care
507 from hospital to home; the role of social networks.

508

509 **List of abbreviations**

510 Academic Hospital Specialist Palliative Care Team (AHSPCT)

511 End of Life (EOL)

512 National Health Service (NHS)

513 Patient Information Sheet (PIS)

514

515 **Declarations**

516 **Ethics approval and consent to participate**

517 When designing, and performing the study, the researchers were guided by ethical standard
518 principles. The research project was reviewed and endorsed by the North West Wales Research

519 Ethics Committee (15/WA/0237). All data collected was stored in line with the University of
520 Liverpool data storage policy (<http://www.liv.ac.uk/csd/regulations/informationsecuritypolicy.pdf>),
521 and handled in confidence in line with the Caldicott principles. Patients received verbal and written
522 information about the study, and they provided their signed informed consent to participate before
523 the interviews took place. Patients were also informed about the voluntary nature of their
524 participation, and that they had the option to withdraw from the study without specifying a reason
525 for doing so, at any time.

526

527 **Consent for publication**

528 Not applicable.

529

530 **Availability of data and materials**

531 The data of this study are available from the corresponding authors on reasonable request.

532

533 **Competing interests**

534 The authors declare that they have no competing interests.

535

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538

539 **Authors' contributions**

540 AB, TM, MG, JE were involved in the process of designing the study. AB conducted the interviews.

541 AB, TM, CRM participated in the data analysis process. AB, TM and CRM wrote the manuscript and

542 MG and JE contributed to the drafting of the manuscript. All authors read and approved the final

543 manuscript.

544

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549

550

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735

736 **Figure Legends**

737 Figure1: Flow Diagram for Recruitment