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Exploration of pain assessment and management processes in oncology outpatient services with healthcare professionals: a qualitative study

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Title:

Exploration of pain assessment and management processes in oncology outpatient services
with healthcare professionals: a qualitative study

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Key words

Pain Assessment, Oncology, Outpatient, Cancer Pain, Pain Management, Qualitative,
Semi-structured interviews.

Abstract

Objectives: This study explored cancer pain management practices and clinical care pathways used by healthcare professionals (HCPs) to understand the barriers and facilitators for standardised pain management in oncology outpatient settings (OS).

Design: Data were collected using semi-structured interviews that were audio-recorded and transcribed. The data was analysed using Thematic Analysis.

Setting: Three NHS trusts with oncology OS in Northern England.

Participants: Twenty HCPs with varied roles (e.g. oncologist, nurse) and experiences (e.g. registrar, consultant) from different cancer site clinics (e.g. breast, lung). Data were analysed using Thematic Analysis.

Results: HCPs discussed cancer pain management practices during consultation and supporting continuity of care beyond consultation. Key findings included: (1) HCPs' level of clinical experience influenced pain assessments; (2) remote consulting impeded experienced HCPs to do detailed pain assessments; (3) diffusion of HCP responsibility to manage cancer pain; (4) nurses facilitated pain management support

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4 with patients; and, (5) continuity of care for pain management was constrained by the
5 integration of multi-disciplinary teams.
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9 **Conclusions:** These data demonstrate HCP cancer pain management practices varied
10 and were unstructured. Recommendations are made for a standardised cancer pain
11 management intervention: (1) detailed evaluation of pain with a tailored self-
12 management strategy; (2) implementation of a structured pain assessment that
13 supports remote consultations, (3) pain assessment tool that can support both
14 experienced and less experienced clinicians. These findings will inform the
15 development of a cancer pain management tool to integrate within routine oncology
16 OS.
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26 **Strengths and Limitations of this study**

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29 - To our knowledge, this study is the first to qualitative study that has explored
30 in-depth cancer pain management processes and experiences in oncology
31 outpatient settings from the perspective of healthcare professionals.
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37 - A structured sampling framework was used to ensure a heterogenous sample
38 of roles, seniority and clinical speciality were recruited to the study, this enabled
39 a detailed understanding to different types of pain prevalence patients
40 experienced.
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49 - Our methodological approach to recruitment may have led to bias, as
50 participants with strong negative or positive views may have been more likely
51 to agree to participate to the study.
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Introduction

In the UK, approximately 167,000 people die of cancer each year (1) of whom half will experience moderate to severe pain, and a third are undertreated for their pain (2, 3).

Under-treatment of cancer pain reduces patients' quality of life and increases healthcare service use and costs (3). For patients, the burden of chronic cancer-pain is associated with anxiety, depression (4) and significantly reduces physical and emotional wellbeing (5).

In the UK and Europe, cancer patients are mainly treated at oncology outpatient services (OS), within secondary or tertiary healthcare systems. Care in OS differs from inpatient hospital settings; outpatient clinics are dedicated services patients visit for specific appointments, so their care can be monitored, reviewed and treated by healthcare professionals (HCPs) (i.e. oncologists, nurses). Despite support given to cancer patients at outpatient clinics, uncontrolled cancer pain is the most common reason for contacting GP out-of-hours services (6).

When cancer pain is routinely assessed on hospital wards or in outpatient clinics, this improves pain control for patients (7). The UK Faculty of Pain Medicine has published Core Standards for cancer pain management (8) which state that cancer patients should receive a pain assessment at each encounter with an oncology clinician that covers intensity, mechanisms, aetiology and impact. Yet, oncology literature shows there is currently no standardised procedure for managing pain in an outpatient setting (9). Despite decades of national and international guidelines on cancer pain

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3 management (10, 11) inadequate pain assessment continues to be a barrier to good
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5
6 pain control for patients with cancer. Wider oncology literature has suggested HCPs
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9 required more educational opportunities for prescribing complex pain relief
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12 medications to cancer patients (12).

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14 External factors can also influence effective pain management processes. In the UK,
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16
17 referral to oncology begins in primary care, this is community-based care provided by
18
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20 general practitioners (GPs). Reduced referrals from primary care during the COVID-
21
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23 19 pandemic has led to an increase in the numbers of patients diagnosed with
24
25
26 advanced cancer post-pandemic. This has been compounded by staff shortages in
27
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29 oncology OS and increasing levels of sickness absence and burnout in the workforce
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32 (13). In the UK, minimal qualitative studies have explored current pain management
33
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35 practices for people with cancer in oncology OS. The aim of this qualitative
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38 investigation was to describe cancer pain management practices and clinical care
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41 pathways for cancer pain management used by healthcare professionals (HCPs) to
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44 understand the barriers and facilitators for standardised pain management in oncology
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47 outpatient settings.
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Methods

Design

Qualitative interview study exploring pain management practices for people with cancer in oncology OS from the perspective of healthcare professionals (HCPs).

Research participants

HCPs were recruited from oncology OS in three National Health Service (NHS) trusts in Northern England. Eligible HCPs were required to have at least 6-months experience of managing cancer pain in an oncology outpatient setting. Purposive sampling was used to recruit participants that had varied job roles (oncologist, clinical nurse specialist (CNS)), with a staff sample to reflect different staff grades (consultant, registrar), working from a range of outpatient sub-specialities (lung, breast, bowel). This ensured a broad range of experiences of cancer pain assessment, support and management for patients with differing disease trajectories were included in the sample.

Recruitment

Eligible HCPs were identified and recruited through co-applicant HCPs embedded within the clinical teams at the respective NHS trusts. Potential participants were emailed a written information sheet explaining the purpose of the study. Interviews

1
2
3 were conducted through telephone and video calling software to suit the participants.
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6 Verbal consent was obtained by OR at the beginning of the interview. The consent
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9 audio was recorded and stored separately to the main interview recording.
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13 **Patient and Public Involvement**

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18 A patient and public involvement (PPI) group contributed to all aspects of the research
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20 design and delivery. It included people with personal experiences of managing cancer
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22 pain and one former carer. One PPI member was also a grant co-applicant.
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27 **Data collection**

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30 Interviews were conducted by OR between March 2022 and May 2022. Sample size
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32 was determined based on previous qualitative studies conducted in oncology OS (14,
33
34 15). Recruitment and analysis continued in tandem until data saturation was reached.
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36
37 An interview topic guide was informed by existing literature and expert input from the
38
39 research and Patient and Public Involvement group (see additional file 1). Participants
40
41 were asked about their experiences of cancer pain management in oncology OS. This
42
43 included exploring current practice, challenges and identifying what could be done to
44
45 improve how pain is managed. OR and MM held weekly meetings to discuss the
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47 interviews and influence of the researcher bias on the dataset was documented.
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Data analysis

Data analysis was done using Braun and Clark's Thematic Analysis (16). With consent from participants, interviews were audio-recorded and transcribed verbatim by OR and LA. Analysis was an inductive-deductive process derived from participant interviews to further explore patterns in the dataset. Initial coding and development of themes was done by OR, MM and SP. This was shared with the wider research team and Patient and Public Involvement and Engagement group to develop, review and refine themes. Anonymised verbatim quotes from the data were used to illustrate and give credibility to findings.

Results

Interviews were conducted with 20 HCPs from three NHS trusts, lasting between 30-minutes to 45-minutes (Table 1. Participant characteristics).

Table 1. Participant characteristics (N=20)

Participant characteristics	
<i>Healthcare professionals (n=20)</i>	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
<i>Cancer sub-speciality area</i>	
Urology	2
Prostate	2
Skin	2
Upper Gastrointestinal tract (GI)	2
Haematology	5

Lung	6
Breast	1

Thematic analysis

Thorough analysis of the transcripts produced two primary themes: (1) *current pain management practices in outpatient consultations* and (2) *delivering continuity of care beyond the oncology consultations* (table 2). Each theme contained four sub-themes to further describe the specific elements of each.

Table 2. Thematic analysis themes and sub-themes

Main theme	Sub-theme
Current pain management practices in outpatient consultations.	Staff background influences pain assessment practice. Assessment of pain was influenced by HCPs seniority and experience, often using clinically based judgements to manage pain.
	Variation in pain management practice. Variation in when and how HCPs approached cancer pain management during consultations, related to time, rapport and location.

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	<p>Remote consulting impact on pain assessment. HCPs felt remote consultations impeded even experienced HCPs ability to do a detailed pain assessment.</p>
	<p>HCP's roles and responsibilities. Varied responsibility felt by HCPs to manage cancer pain.</p>
<p>Continuity of care following oncology consultations</p>	<p>Utilisation of outpatient oncology CNS. HCPs felt oncology CNS had more time to build rapport with patients outside the consultation, and provide a personalised continuity of care making patients more willing to openly disclose their pain.</p> <p>Integration of supportive services. Optimal pain management involved HCPs identifying and monitoring pain whilst utilising supportive services (i.e. pain management teams) for advice and guidance to develop appropriate treatment pathways.</p> <p>Re-assessment and monitoring of cancer pain between primary and secondary care. Outpatient clinicians' opportunity to re-assess and monitor cancer pain is constrained by the frequency of appointments.</p> <p>Self-management plans to manage cancer pain at home. HCPs created self-</p>

	management plans for patient to ensure their cancer pain was adequately reviewed.
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Current pain management practices in outpatient consultations

Participants reported factors such as time, rapport, mode of assessment (i.e. telephone) and diffusion of responsibility influenced the extent pain management was explored with patients.

Staff background influences pain assessment practice

Assessment of pain in outpatient clinics was influenced by individual HCP's seniority and experience. Experienced consultants expressed confidence assessing and treating cancer pain because it was an area of care they *"do a lot of"*[P012]. Experienced HCPs stated *"I don't use any pain guidelines"*[P011] or *"I just pull on my own experience"*[P013] to describe how pain was assessed in practice. Senior staff appeared more likely to use tacit knowledge in addition to drawing on clinically based observations (i.e. non-verbal behaviours) and conversations with the patient before determining an appropriate treatment plan:

"They [the HCP] might be looking at how far can you lift the leg, the pressure that they can put on the leg and how much feeling there is on the leg" P004 [CNS, haematology clinic]

HCPs used open-ended questions that *"triggered"*[P011] patients to discuss pain or discomfort followed by an assessment for severity of pain. Using a verbal description of a numerical pain intensity scale encouraged patients to *"score it, 0-10"*[P009]. Yet,

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3 several HCPs felt pain scales did not provide a valid representation of a patient's pain
4
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6 because the subjective nature of pain made it *"difficult to apply to numbers"*- [P006].
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8 Asking questions associated with the type of cancer, initiated patients to think in-depth
9
10 about the context, triggers, occurrences and nature of the pain:
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12

13
14 *"Thoracic cancers I'd always ask about chest pain specifically and risk of pain*
15
16 *or swelling outside of the chest and with gynaecological cancers I'd say "have*
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18 *you had any abdominal pain or bloating" P008 [Registrar, lung clinic]*
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26 Variation in pain management practice

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29 There was variation in when and how HCPs approached cancer pain management
30
31 during consultations, related to time, rapport and location. Participants stated pain
32
33 management conversations required *"empathy and sensitivity"* – [P001], yet
34
35 developing the necessary rapport took time. Participants suggested patients received
36
37 pain assessments at different points in a care journey, i.e. initial or follow-up
38
39 consultations. HCPs acknowledged the extent to which pain management was
40
41 approached and communicated to patients depended on specific diagnosis groups
42
43 with differing levels of associated pain. If HCPs were seeing a *"new cancer patient*
44
45 *with less pain"*- [P008] consultants prioritised other areas of the patient's care (i.e.
46
47 arranging treatment, discussing patient concerns):
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4 *"If I'm consenting them for radiotherapy a lot of them won't really be having any*
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6 *pain, so you know I'll ask, and if they're saying no, then that's fine" P008*
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8
9 *[Registrar, Lung clinic]*
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11
12 HCPs suggested discussing other areas of cancer-related care meant opportunities
13
14 for an in-depth, detailed pain assessment were potentially lost. For patients with
15
16 specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment
17
18 identified pain management as a priority. HCPs made clinical judgements on the
19
20 extent and timing of pain management discussions. This included recognising when
21
22 external factors could potentially exacerbate pain, for example, "*frailty in older patients,*
23
24 *comorbidities or smoking*" - [P003].
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31 *"Some patients are straightforward. Whereas a lot of lung patients have been*
32
33 *heavy smokers. They've got COPD and ischemic heart disease...where you*
34
35 *really have got to get into conversations about pain in a big way" P003*
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39 *[Consultant, haematology clinic]*
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41
42 HCPs suggested follow-up consultations were variable and depended on the care
43
44 needs and severity of the patient's cancer. For patients with advanced cancer that
45
46 were seen weekly it could be easier to monitor and explore pain. HCPs described
47
48 difficulties with building rapport to explore pain when appointments were infrequent
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50 and patients did not see the same HCP at follow-up appointments.
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Remote consulting impact on pain assessment

Management of oncology outpatient care has changed since COVID-19 pandemic and more consultations are conducted remotely. HCPs described advantages to remote consulting as it enabled easier, more frequent contact with patients and supported continuity of care:

"We would, you know put that as part of our diary for the following day to call back and see. Make sure that it was working" P005 [CNS, upper GI clinic]

However, some HCPs found remote consulting prevented non-verbal observations of pain and experienced clinicians recognised that this impeded their ability to do a detailed pain assessment:

"And saying to a patient, is it the lumbar region? Why would they know that" P004 [CNS, haematology clinic]

HCPs described a risk of patients misattributing cancer-related pain for side effects and symptoms during remote consultations, making it challenging to provide appropriate treatment. HCPs had to *"take [it] on the patient's own word"*-[P002] feeling there was *"no other option"*- [P002]. Some HCPs felt pain assessments began from observations of non-verbal cues when *"they call the patient from the waiting room"*- P011, which was not possible in telephone consultations. This contributed to the overall judgement of the patient's pain:

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4 *“You notice whether they’re in a wheelchair, how they’re able to get out of their*
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6 *chair, whether they can walk down the corridor as fast or slower than you can”*
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9 *P018 [Consultant, breast clinic].*

Healthcare professional’s roles and responsibilities

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18 There was a diffusion of responsibility when HCPs discussed pain management. Due
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20 to other community-based HCPs (i.e. GPs, palliative care teams) also being able to
21
22 monitor and manage a patient’s pain, some oncologists in secondary care felt it was
23
24 not their responsibility therefore did not engage in detailed pain conversations, e.g. it
25
26 was a *“community palliative nurse’s job to manage pain”- [P003]*. However, HCPs did
27
28 not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss
29
30 this pain with the patient’s community teams and thus developed a self-management
31
32 plan for the patient to follow:
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40 *“You’re thinking about, well, the patient could be suffering tonight. You know, I*
41
42 *can maybe address some of these issues now” P003 [Consultant, haematology*
43
44 *clinic].*

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48 Some HCPs described how patients needed to take *“ownership”-[P014]* and
49
50 *“responsibility”-[P003]* to disclose if they were experiencing pain because patients
51
52 often withheld the extent of their pain due to *“fears of bothering the clinician”- [P008]*
53
54 making it more challenging to accurately assess and manage. In some instances,
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4 HCPs felt patients needed to provide honest opinions to support a thorough
5
6 assessment and avoid uncontrolled pain:
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10 *"You know autonomy to the patient and responsibility to the patient to tell you if*
11
12 *there's a problem you know" P014 [Registrar, upper GI clinic]*
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21 22 **Continuity of care following outpatient consultations**

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24 Participants indicated continuity of care for pain management was facilitated by CNS,
25
26 relationships between oncology HCPs and supportive services (i.e. palliative care
27
28 teams, pain management services), re-assessment and monitoring of cancer pain
29
30 between primary and secondary care and self-management plans to manage cancer
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32 pain at home.
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37 38 **Utilisation of outpatient oncology CNS**

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40 Most registrars and consultants entrusted CNS with following up patients and
41
42 providing pain management support beyond their initial consultation with an
43
44 oncologist. This was a component of the CNS role to undertake follow-up remote
45
46 consultations (i.e. telephone or video call) including the re-assessment of pain and
47
48 other symptoms:
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54 *"I have the support of CNSs, it will be within days [referring to follow-up calls],*
55
56 *you know hopefully within a week then I have somebody else checking in on*
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4 *them as to whether medication levels need increasing” P007 [Consultant,*
5
6 *prostate clinic].*
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9 Consultants reflected on a CNS ability to build rapport with patients and provide a
10 personalised continuity of care making patients more willing to openly disclose their
11 pain. One example showed CNS identifying problematic pain with a patient and
12 escalating this to the consultant to be explored further at follow-up consultations so
13 changes can be made to medication:
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23 *“If there's a note or a, verbal reminder [referring to a nurse providing notes to a*
24 *consultant about a patient's pain]. Actually, they have had some problems with*
25 *pain or this particular issue then that definitely works well” P011 [Consultant,*
26 *haematology clinic].*
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34 If there were little or no CNS staff available to support the management of pain
35 following consultations with an oncologist, participants suggested it placed strain on
36 other HCPs to fulfil this role. Consultants and registrars expressed concerns for having
37 *“triple booked clinics”- [P003]* and calling patients *“three hours after their appointment*
38 *time”-[P003]* when there were no CNS staff to support clinics.
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51 Integration of supportive services

52 Relationships between supportive services (i.e. palliative care, community nursing
53 teams and pain team) and oncology HCPs were essential to cancer pain management.
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59 While HCPs expressed confidence in their ability to identify and treat cancer pain,
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3 there were circumstances where HCPs described “*reaching their limits*”- [P012] on
4
5 providing recommendations on complex opioid medication and required specialist
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8 support:
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12 *“we’re used to drugs like Gabapentin, Amitriptyline but when patients are still*
13
14 *having pain, that’s when you need help and we’re lucky, we can ring the palliative*
15
16 *care team and there is somebody that can review the patient...usually you can get*
17
18 *access to that specialist advice if you need”.*P012 [Consultant, lung clinic]
19
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22 In some cases, the level of responsibility and expertise the clinician felt they had over
23
24 managing a patient’s pain (i.e. pain was important part of consultation discussions)
25
26 influenced whether a patient would be referred to another team or managed by
27
28 themselves. Data suggested optimal pain management often involved HCPs
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30 identifying and monitoring pain whilst utilising supportive services for advice and
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32 guidance to develop appropriate treatment pathways.
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42 Re-assessment and monitoring of cancer pain between primary and secondary
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44 care
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47 Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make
48
49 amendments to medication more frequently. In OS a clinicians’ opportunity to re-
50
51 assess and monitor cancer pain was constrained by the frequency of appointments on
52
53 weekly, monthly or greater basis. Some oncology OS support patients from “*large*
54
55 *geographical areas*”-[P005] therefore patients might not return for consistent follow-up
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4 appointments. Participants reported this made it difficult for HCPs to provide continuity
5
6 of care and put more dependency on managing cancer pain between primary and
7
8 secondary care:
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12 *“What we don't have a mechanism like we do on the ward... We simply don't*
13
14 *have that contact, so we are next seeing the patients usually in three or six*
15
16 *weeks' time. So the pattern of medical interaction it simply doesn't map on to*
17
18 *pain relief” P018 [Consultant, breast clinic]*
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23 HCPs emphasised pain management decisions needed to be made in line with the
24
25 patient's needs and their ability to conveniently access primary care. As a result of
26
27 this, patients and HCPs often had to *“rely on the GPs to issue drugs and escalate pain*
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29 *control”- [P014].*
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34 *“We would also encourage patients to seek support from the GP and there will*
35
36 *come a time when it's beyond our scope” P005 [CNS, upper GI clinic]*
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44 Self-management plans to manage cancer pain at home

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46 Due to the challenges with assessment and re-assessment in OS, some HCPs
47
48 suggested providing a *“safety net”-[P016]*for the patient was a crucial aspect to ensure
49
50 cancer pain was adequately reviewed. This involved developing a strategy so a patient
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52 knew what to do if the pain relief was not effective or if they were still experiencing
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54 severe pain:
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4 *"I want you to see how those go and then perhaps give them a time period, so this*
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6 *is gonna take a few days for this to start to work better. If things are not any better,*
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8 *then to call us back" P016 [Consultant, haematology clinic]*

10
11 Some HCPs provided patients with documentation that included information on how,
12
13 when and what medication to take, as well as contact information for the OS and out-
14
15 of-hours services. This was one-way HCPs ensured patients were supported to self-
16
17 manage cancer pain at home:
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22 *"If there is anything of concern there is a number that you can call 24 hours a*
23
24 *day, 7 days a week, 365 days a year and then we can see them on the acute*
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26 *unit and take it from there" P006 [Registrar, urology clinic]*
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Discussion

We found an unstructured and variable approach to pain management affected multiple components of a patient's outpatient cancer care. Firstly, HCPs used clinical judgement in place of a structured assessment to manage a patient's pain. This explains why HCPs might not use pre-existing guidelines and tools that have been published (10, 11). Research has highlighted disadvantages to using pain assessment tools, such as oversimplification of the multi-dimensional pain experience and not an appropriate reflection of a patient's pain (17). Pain management tools can be efficient especially when HCPs have limited time or when pain assessments are combined with individualised assessment to fully understand how pain is affecting the patient physically, psychologically, socially and culturally.

As shown in this study, the diffusion of responsibility that the respective healthcare professional placed on managing a patient's pain influenced the extent pain was explored with patients. Implementation of a structured pain assessment used by all HCPs ensures all patients receive a consistent thorough assessment of pain. This could be used in conjunction with the recognition of non-verbal cues and open-ended questions to explore the patient's pain in more detail. We found variation across the roles and responsibilities of HCPs supporting the continuity of pain management. Oncology outpatient literature suggests some HCPs perceived their primary duty was to provide patients with their disease status and have conversations around treatment (18). However, our data shows that HCPs who expressed clinical responsibility around

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4 pain management were inclined to develop self-management plans to support patients
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6 to manage cancer pain at home.
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9 This study aimed to describe current pain management and thus the interview topic
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11 guide was not developed to explore nuances of self-management practices.
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14 However, we know from previous studies there is variation in self-management
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16 approaches (19). In OS, development of self-management support for patients is
17
18 crucial to a continuity of care. This includes providing elements of educational
19
20 interventions to facilitate problem solving and adequate decision-making skills and
21
22 tailoring recommendations to the individual's situation and defining goals with action
23
24 plans (19). By developing supportive plans, it ensures patients understand what to do
25
26 if pain escalates or becomes unmanageable. Subsequently, it could encourage
27
28 patients to initiate re-assessment of their pain at primary and secondary care services.
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36 We found system-level challenges impacted the extent to which pain was explored
37
38 with patients and monitored by outpatient HCPs. Exacerbated by the impact of the
39
40 COVID-19 pandemic, clinics are often over-booked, short staffed, and have long
41
42 waiting lists (13). In addition, our data show that the complexity surrounding the
43
44 interface between primary and secondary care and challenges with integration of
45
46 multi-disciplinary teams meant continuity of care, in particular re-assessment and
47
48 monitoring of pain, was difficult as patients were referred back to primary or community
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50 care teams.
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4 Oncologists found it difficult to build rapport with patients that might not return to
5
6 outpatient appointments and felt they had to prioritise topics of care with the limited
7
8 time they had. Consultations take a patient-centred approach that prioritises care
9
10 practices that are responsive to a patient's preferences and values and thus not
11
12 focusing on pain management may be appropriate for some patients. However, this
13
14 study and previous research has highlighted patients can often be reluctant to express
15
16 their concerns and preferences without prompting (9). This suggests the development
17
18 of rapport with patients is essential to gain full understanding of a patient's care needs.
19
20 We found CNS had more opportunities to build rapport and have discussions about
21
22 pain with patients. However, in line with previous studies (12) opportunities for pain
23
24 management discussions are often missed if there are nurses with less experience
25
26 and confidence to conduct pain assessments. Recommendations from this study
27
28 highlight the benefit of providing training for HCPs to support pain management
29
30 conversations and embedding this within routine clinical practice.
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41 Oncology literature has highlighted the benefits for the use of remote consultations in
42
43 cancer pain management, where it is used appropriately. For example, reduction in
44
45 pain severity scores, cost-effective, improved accessibility for patients to receive HCP
46
47 advice and treatment of symptoms and aided monitoring and re-assessment of
48
49 symptoms (20, 21). We found adaptations to pain assessments for remote care
50
51 impeded experienced HCPs to do a detailed thorough pain assessment, especially if
52
53 not Audio Visual (AV) facilitated. HCPs become experts in their field through
54
55 knowledge, skill, training and experiential learning (22). Since COVID-19 the increased
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3 use of remote consultations has meant HCPs have to spend more time doing pain
4 assessments remotely. However, due to a lack of experiential learning for conducting
5
6 pain assessments through remote consultations, this potentially made even
7
8 experienced HCPs feel like a novice. This coincides with the novice to expert theory
9
10 (22). Similarly, for those with less experience a change in mode-of-consulting could
11
12 further impede thorough pain assessments for patients. Without additional support and
13
14 structured guidance on how to conduct remote consultations there is a risk that
15
16 patients' pain will not be appropriately managed and key components of a detailed
17
18 pain assessment potentially missed. Previous research has shown even when pain
19
20 assessments are standardised and detailed, only modest improvements in pain for
21
22 patients with cancer are observed, largely because of low delivery fidelity and poor
23
24 implementation (10). However, Fallon et al. (2018) demonstrated that when
25
26 standardised pain assessment processes are integrated within routine clinical practice
27
28 at the level of the service (rather than at an individual clinician level) this leads to
29
30 greater improvements in pain outcomes for patients and more appropriate analgesic
31
32 prescribing. This suggests an in-depth implementation plan at service-level would be
33
34 crucial to the success of a structured pain management intervention.
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51 Strengths and limitations

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53 A structured sampling framework was developed by the research team which may
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55 have resulted in potential bias. However, this approach provided a heterogeneous
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4 sample of staff roles, seniority and clinical speciality that gave a greater understanding
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6 to the management of different types of pain prevalence patients experienced. A
7
8 limitation of our methodological approach is related to recruitment bias; due to the
9
10 nature of the research aims (i.e. pain management in oncology) participants with
11
12 strong negative or positive views may have been more likely to agree to participate.
13
14
15 However, the themes identified from the data indicated broad perspectives of pain
16
17 management processes and experience, so it is unlikely that we have sampled an
18
19 exclusively polarised group of participants.
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30 Implications of clinical research and practice

31 Faculty of Pain Medicine Core standards for cancer pain management (8) state all
32
33 patients should receive a pain assessment at each encounter with an oncology
34
35 clinician that includes exploration of intensity, mechanisms, aetiology and impact.
36
37 Evidence from clinical trials show that standardising pain assessment in oncology
38
39 outpatient clinics leads to improvements in patients' pain and quality of life (7). This
40
41 research recommends the implementation of a structured routine pain assessment
42
43 that enables all HCPs using different modes of consultations to incorporate the most
44
45 crucial components of a pain assessment within the limited time they have. Secondly,
46
47 at a service level, uncontrolled cancer pain remains the most common reason for
48
49 contacting GP out-of-hours service (6). Implementing a structured pain assessment
50
51 within oncology OS would encourage patients to report pain earlier, enabling HCPs to
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3 manage cancer pain earlier, reducing the burden on GP out-of-hours service, and
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5
6 minimising the risk of patients living with undertreated cancer pain.
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9 Conclusion

10
11 This study demonstrates a variable and unstructured approach to pain management
12
13 affected multiple components of a patient's outpatient cancer care. We recommend
14
15 the need for a cancer pain management intervention that standardises pain
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17 assessments in oncology OS, which is implemented at the level of the service. This
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19 will ensure each patient receives the same detailed evaluation of cancer pain and is
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21 provided with a self-management strategy that facilitates pain management beyond
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23 consultations.
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34 List of abbreviations

35
36
37 HCP – Healthcare Professionals
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40 OS – Outpatient Services
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44 CNS – Clinical Nurse Specialist
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47 Upper GI - Upper Gastrointestinal tract
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51 NHS – National Health Service
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54 AV – Audio Visual
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Declarations

Ethical approval and consent to participate

Ethical approval was obtained by University of Leeds, Faculty of Medicine Research Ethics Committee and Health Research Authority (21/HRA/5245). Approvals were also obtained at each NHS trust.

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests statement

None declared.

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Authors' contribution

1
2
3
4 MM is the chief investigator for this study; he conceived the project, led the design and
5
6 writing of the study protocol, facilitated data analysis and drafting of this manuscript.
7
8

9
10 OR facilitated the writing of the study protocol, including drafting the topic guide,
11
12 completed data collection and transcribed interviews. OR led the data analysis
13
14 facilitated by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. All
15
16 authors contributed to manuscript revision, read and approved the submitted version.
17
18

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28

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For peer review only



The Capture Study

Improving pain control for people living with cancer

Interview topic guide

❖ **Professional Background**

(role, experience, knowledge/training in pain assessment and management, contact with advanced cancer patients)

❖ **Experiences of conducting pain assessments to support to people with advanced cancer**

- Assessment
 - Basic: pain intensity and interference
 - Detailed: underlying aetiology and pain mechanism, linked analgesic prescribing
- Decision-making
- Access to cancer pain management guidelines
- Providing cancer treatments and care
- Communication between oncology and patient
- Follow-up contact between patient and hcp

❖ **Identifying triggers for pain assessment**

- *what factors would lead doctor or nurse to undertake a pain assessment*

❖ **Specific examples of cancer pain assessments that have been conducted**

- *Talk us through how pain is assessed and managed in practice*

❖ **Examples of existing tools used in everyday pain assessment practice**

- *What works with this pain assessment tool or needs improving?*
- *Any challenges with using the tools in everyday practice?*

❖ **Anything that is difficult when people have advanced cancer to assess and manage their pain?**

❖ **Anything that works well?**

N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.



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❖ ***Suggestions for how pain assessment could be improved for people with advanced cancer?***

14 To ask participants that have insight and knowledge into existing clinical pathways:

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❖ ***Implementing routine pain assessment within existing clinical pathways***

- Describe how a new treatment or procedure is currently integrated into an outpatient service?
- Who is responsible for making sure everyone is trained and using the new treatment or procedure?
- How can routine pain assessments be integrated into existing clinical pathways in your oncology outpatient service?
- Explain what these improvements might make?
- Any potential system level challenges?

❖ ***Anything you would like to add?***

N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.



SRQR 21-point checklist

No.	Topic	Completed	Page no.
1.	Title	<input checked="" type="checkbox"/>	1
2.	Abstract	<input checked="" type="checkbox"/>	2
3	Problem formulation	<input checked="" type="checkbox"/>	3
4.	Purpose or research question	<input checked="" type="checkbox"/>	4
5.	Qualitative approach	<input checked="" type="checkbox"/>	4
6.	Research characteristics and reflexivity	<input checked="" type="checkbox"/>	5
7.	Context	<input checked="" type="checkbox"/>	4
8.	Sampling strategy	<input checked="" type="checkbox"/>	4
9.	Ethical Issues	<input checked="" type="checkbox"/>	5/18
10.	Data collection methods	<input checked="" type="checkbox"/>	5
11.	Data collection instruments and technologies	<input checked="" type="checkbox"/>	5
12.	Units of study	<input checked="" type="checkbox"/>	6
13.	Data processing	<input checked="" type="checkbox"/>	5
14.	Data analysis	<input checked="" type="checkbox"/>	6/7
15.	Techniques to enhance trustworthiness	<input checked="" type="checkbox"/>	5
16.	Synthesis and interpretation	<input checked="" type="checkbox"/>	5
17.	Links to empirical data	<input checked="" type="checkbox"/>	8-13
18.	Integration with prior work, implications, and contribution to field	<input checked="" type="checkbox"/>	14-16
19.	Limitations	<input checked="" type="checkbox"/>	16
20.	Conflict of interest	<input checked="" type="checkbox"/>	18
21.	Funding	<input checked="" type="checkbox"/>	18

BMJ Open

Exploration of pain assessment and management processes in oncology outpatient services with healthcare professionals: a qualitative study

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Primary Subject Heading:	Oncology
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Keywords:	Cancer pain < ONCOLOGY, QUALITATIVE RESEARCH, Adult oncology < ONCOLOGY

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6 2 **Title:**
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9 3 Exploration of pain assessment and management processes in oncology outpatient services
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11 4 with healthcare professionals: a qualitative study
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16
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16 27 **Key words**

17
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19 28 Pain Assessment, Oncology, Outpatient, Cancer Pain, Pain Management, Qualitative,

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22 29 Semi-structured interviews.

23
24
25 30 **Abstract**

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28 31 **Objectives:** This study explored cancer pain management practices and clinical care
29 32 pathways used by healthcare professionals (HCPs) to understand the barriers and
30 33 facilitators for standardised pain management in oncology outpatient settings (OS).

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34 35 **Design:** Data were collected using semi-structured interviews that were audio-
35 36 recorded and transcribed. The data was analysed using Thematic Analysis.

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38 38 **Setting:** Three NHS trusts with oncology OS in Northern England.

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41 40 **Participants:** Twenty HCPs with varied roles (e.g. oncologist, nurse) and experiences
42 41 (e.g. registrar, consultant) from different cancer site clinics (e.g. breast, lung). Data
43 42 were analysed using Thematic Analysis.

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46 44 **Results:** HCPs discussed cancer pain management practices during consultation and
47 45 supporting continuity of care beyond consultation. Key findings included: (1) HCPs'
48 46 level of clinical experience influenced pain assessments; (2) remote consulting
49 47 impeded experienced HCPs to do detailed pain assessments; (3) diffusion of HCP
50 48 responsibility to manage cancer pain; (4) nurses facilitated pain management support

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4 49 with patients; and, (5) continuity of care for pain management was constrained by the
5 50 integration of multi-disciplinary teams.
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9 52 **Conclusions:** These data demonstrate HCP cancer pain management practices varied
10 53 and were unstructured. Recommendations are made for a standardised cancer pain
11 54 management intervention: (1) detailed evaluation of pain with a tailored self-
12 55 management strategy; (2) implementation of a structured pain assessment that
13 56 supports remote consultations, (3) pain assessment tool that can support both
14 57 experienced and less experienced clinicians. These findings will inform the
15 58 development of a cancer pain management tool to integrate within routine oncology
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24 25 26 61 **Strengths and Limitations of this study**

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28 62 - To our knowledge, this is one of the first qualitative studies that has provided a
29 63 descriptive account of cancer pain management processes and experiences in
30 64 oncology outpatient settings from the perspective of healthcare professionals.
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35 66 - A structured sampling framework was used to ensure a heterogeneous sample
36 67 of roles, seniority and clinical speciality were recruited to the study. This
37 68 enabled a detailed understanding to different types of pain prevalence patients
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45 71 - Our recruitment strategy (i.e. self-referral sampling after receiving an
46 72 information pack) may have led to bias, as individuals with strong negative or
47 73 positive views may have been more likely to self-refer and agree to participate
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76 Introduction

77 In the UK, approximately 167,000 people die of cancer each year (1) of whom half will
78 experience moderate to severe pain, and a third are undertreated for their pain (2, 3).

79 Under-treatment of cancer pain reduces patients' quality of life and increases
80 healthcare service use and costs (3). For patients, the burden of chronic cancer-pain
81 is associated with anxiety, depression (4) and significantly reduces physical and
82 emotional wellbeing (5).

83 The underlying pathophysiology of cancer pain is complex; nociceptive, inflammatory,
84 and neuropathic mechanisms exist in concert with psychological and emotional
85 components of chronic pain, making cancer pain challenging to manage clinically (6)
86 (7). Historically, the management of cancer pain has been based on evaluating the
87 subjective intensity of pain (via 0-10 Likert scales) (8) which do not evaluate aetiology,
88 mechanisms or psychological components of pain (9). In addition, the challenging
89 clinical environment within an oncology outpatient department means that cancer pain
90 management is one of many competing priorities that healthcare professionals (HCPs)
91 must manage during a time-limited consultation. In the UK and Europe, cancer
92 patients are mainly treated at oncology outpatient services (OS), within secondary or
93 tertiary healthcare systems. Care in OS differs from inpatient hospital settings;
94 outpatient clinics are dedicated services patients visit for specific appointments, so
95 their care can be monitored, reviewed and treated by HCPs (i.e. oncologists, nurses).
96 Despite support given to cancer patients at outpatient clinics, uncontrolled cancer pain
97 is the most common reason for contacting GP out-of-hours services (10).

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4 98 When cancer pain is routinely assessed on hospital wards or in outpatient clinics, this
5
6 99 improves pain control for patients (11). The UK Faculty of Pain Medicine has published
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8
9 100 Core Standards for cancer pain management (12) which state that cancer patients
10
11 101 should receive a pain assessment at each encounter with an oncology clinician that
12
13
14 102 covers intensity, mechanisms, aetiology and impact. Yet, oncology literature shows
15
16 103 there is currently no standardised procedure for managing pain in an outpatient setting
17
18
19 104 (13). Despite decades of national and international guidelines on cancer pain
20
21 105 management (6, 8) inadequate pain assessment continues to be a barrier to good pain
22
23 106 control for patients with cancer. Wider oncology literature has suggested HCPs
24
25 107 required more educational opportunities for prescribing complex pain relief
26
27 108 medications to cancer patients (14).
28
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32
33 109 External factors can also influence effective pain management processes. In the UK,
34
35 110 referral to oncology begins in primary care, this is community-based care provided by
36
37 111 general practitioners (GPs). Reduced referrals from primary care during the COVID-
38
39 112 19 pandemic has led to an increase in the numbers of patients diagnosed with
40
41 113 advanced cancer post-pandemic. This has been compounded by staff shortages in
42
43 114 oncology OS and increasing levels of sickness absence and burnout in the workforce
44
45
46 115 (15). In the UK, minimal qualitative studies have explored current pain management
47
48 116 practices for people with cancer in oncology OS. The aim of this qualitative
49
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51 117 investigation was to describe cancer pain management practices and clinical care
52
53 118 pathways for cancer pain management used by HCPs to understand the barriers and
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56 119 facilitators for standardised pain management in oncology OS.
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4 1205
6 121 **Methods**7
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12 123 **Design**13
14 124 Qualitative interview study exploring pain management practices for people with
15 125 cancer in oncology OS from the perspective of HCPs.
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21
22 127 **Research participants**23
24 128 HCPs were recruited from oncology OS in three National Health Service (NHS) trusts
25 129 in Northern England. Eligible HCPs were required to have at least 6-months
26 130 experience of managing cancer pain in an oncology outpatient setting. Purposive
27 131 sampling was used to recruit participants that had varied job roles (oncologist, clinical
28 132 nurse specialist (CNS)), with a staff sample to reflect different staff grades (consultant,
29 133 registrar), working from a range of outpatient sub-specialities (lung, breast, bowel).
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41 134 This ensured a broad range of experiences of cancer pain assessment, support and
42
43
44 135 management for patients with differing disease trajectories were included in the
45
46 136 sample.
47
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52 138 **Recruitment**53
54 139 Eligible HCPs were identified and recruited via co-applicant HCPs embedded within
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56
57 140 the clinical teams, who emailed study information packs (i.e. information sheet,
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4 141 consent form) to their entire clinical teams. Contact information of the research team
5
6 142 (OR/MM) was included in study information packs and potentially eligible participants
7
8
9 143 were asked to contact the research team (OR/MM). When potentially eligible
10
11 144 participants contacted the research team (OR/MM) the study was discussed in detail,
12
13
14 145 any questions answered, and a date/time arranged for an interview. Interviews were
15
16 146 conducted through telephone and video calling software to suit the participants. Verbal
17
18
19 147 consent was obtained by OR at the beginning of the interview. The consent audio was
20
21
22 148 recorded and stored separately to the main interview recording.
23

24 149

26 150 **Patient and Public Involvement**

29 151

31 152 A patient and public involvement (PPI) group was established at the beginning of the
32
33 153 project. Our PPI group included people with personal experiences of managing cancer
34
35
36 154 pain and one former carer. One PPI member was also a grant co-applicant. The PPI
37
38
39 155 group met during the study development phase to contribute to the design and delivery
40
41 156 methods. This included providing feedback on the development of study documents
42
43
44 157 and processes. Once data had been collected, transcribed and summarised the PPI
45
46
47 158 group met to provide feedback on the initial themes and sub-themes identified from
48
49 159 the data.
50

51 160

54 161 **Data collection**

56 162 Interviews were conducted by OR between March 2022 and May 2022. Sample size
57
58
59 163 was determined based on previous qualitative studies conducted in oncology OS (16,
60

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4 164 17). Recruitment and analysis continued in tandem until data saturation was reached.
5
6 165 An interview topic guide was informed by existing literature and expert input from the
7
8
9 166 research and Patient and Public Involvement group (see additional file 1). Participants
10
11 167 were asked about their experiences of cancer pain management in oncology OS. This
12
13
14 168 included exploring current practice, challenges and identifying what could be done to
15
16
17 169 improve how pain is managed. OR and MM held weekly meetings to discuss the
18
19 170 interviews and influence of researcher bias on the dataset was documented.
20
21
22 171

171

172 **Data analysis**

23
24
25
26 173 Data analysis was done using Braun and Clark's Thematic Analysis (18). With consent
27
28 174 from participants, interviews were audio-recorded and transcribed verbatim by OR and
29
30
31 175 LA. Analysis was an inductive-deductive process derived from participant interviews;
32
33
34 176 preliminary analyses was undertaken throughout the data collection process and the
35
36
37 177 topic guide was adjusted accordingly to explore existing and new patterns identified
38
39 178 within the data. After familiarising themselves with the transcripts, initial coding and
40
41
42 179 development of themes was done by OR, MM and SP. Through a series of data
43
44 180 analysis meetings, the initial themes and sub-themes were presented to the wider
45
46
47 181 research team and our PPI group to explore their meaning and significance. During
48
49
50 182 these meetings each theme and sub-theme was described in detail and supporting
51
52 183 evidence (codes and quotes) was presented and discussed. Following each data
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54
55 184 analysis meeting the themes and sub-themes were refined in an iterative process until
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4 185 the themes were agreed. Anonymised verbatim quotes from the data were used to
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6 186 illustrate and give credibility to findings.
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188 **Results**

189 Interviews were conducted with 20 HCPs from three NHS trusts, lasting between 30-
 190 minutes to 45-minutes (Table 1. Participant characteristics).

191

192 *Table 1. Participant characteristics (N=20)*

Participant characteristics	
<i>Healthcare professionals (n=20)</i>	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
<i>Cancer sub-speciality area</i>	
Urology	2
Prostate	2
Skin	2
Upper Gastrointestinal tract (GI)	2
Haematology	5

Lung	6
Breast	1

193

194

195 **Thematic analysis**

196 Thorough analysis of the transcripts produced two primary themes: (1) *Pain*
 197 *management practices during oncology outpatient consultations* and (2) *delivering*
 198 *continuity of care beyond oncology outpatient consultations* (table 2). Each theme
 199 contained four sub-themes to further describe the specific elements of each.

200

201

202 *Table 2. Thematic analysis themes and sub-themes*

Theme 1: Pain management practices during oncology outpatient consultations

Sub-themes:

1.1 Staff experience influenced pain assessment practice

Assessment of pain was influenced by HCPs seniority and experience, often using clinically based judgements to manage pain.

1.2 Variation in pain management practice

There was variation in when and how HCPs approached cancer pain management during consultations, related to time and rapport.

1.3 Remote consulting impacted pain assessment

HCPs felt remote consultations impeded even experienced HCPs ability to perform a detailed pain assessment.

1.4 HCP's roles and responsibilities

There was variation in the extent to which HCPs felt responsible to manage cancer pain.

Theme 2: Continuity of care following oncology outpatient consultations

Sub-themes:

2.1 Utilisation of outpatient oncology clinical nurse specialists

HCPs felt oncology speciality nurses had more time to build rapport with patients and enable patients to openly disclose their experience of cancer pain.

2.2 Integration of supportive services

Optimal pain management involved utilising supportive services (i.e. pain management teams) for advice and guidance to develop appropriate treatment pathways.

2.3 Reassessment and monitoring of cancer pain between primary and secondary care

Outpatient clinicians' opportunity to re-assess and monitor cancer pain is constrained by the frequency of appointments.

2.4 Providing patients with supported self-management plans to manage cancer pain at home

HCPs created self-management plans for patient to ensure their cancer pain was adequately reviewed.

203

204 Pain management practices during oncology outpatient consultations

205 Participants reported factors such as time, rapport, mode of assessment (i.e.
206 telephone) and diffusion of responsibility influenced the extent pain management was
207 explored with patients.

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4 208 Staff experience influenced pain assessment practice

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6 209 Assessment of pain in outpatient clinics was influenced by individual HCP's seniority
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8
9 210 and experience. Experienced consultants expressed confidence assessing and
10
11 211 treating cancer pain because it was an area of care they *"do a lot of"*-[P012].
12
13
14 212 Experienced HCPs stated *"I don't use any pain guidelines"*-[P011] or *"I just pull on my*
15
16 213 *own experience"*-[P013] to describe how pain was assessed in practice. Senior staff
17
18
19 214 appeared more likely to use tacit knowledge in addition to drawing on clinically based
20
21
22 215 observations (i.e. non-verbal behaviours) and conversations with the patient before
23
24
25 216 determining an appropriate treatment plan:

26
27
28 217 *"They [the HCP] might be looking at how far can you lift the leg, the pressure*
29
30 218 *that they can put on the leg and how much feeling there is on the leg"* P004
31
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33 219 *[CNS, haematology clinic]*

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35
36 220 HCPs used open-ended questions that *"triggered"*-[P011] patients to discuss pain or
37
38
39 221 discomfort followed by an assessment for severity of pain. Using a verbal description
40
41
42 222 of a numerical pain intensity scale encouraged patients to *"score it, 0-10"*-[P009]. Yet,
43
44
45 223 several HCPs felt pain scales did not provide a valid representation of a patient's pain
46
47 224 because the subjective nature of pain made it *"difficult to apply to numbers"*- [P006].
48
49
50 225 Asking questions associated with the type of cancer, initiated patients to think in-depth
51
52 226 about the context, triggers, occurrences and nature of the pain:
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4 227 *“Thoracic cancers I’d always ask about chest pain specifically and risk of pain*
5
6 228 *or swelling outside of the chest and with gynaecological cancers I’d say “have*
7
8 229 *you had any abdominal pain or bloating” P008 [Registrar, lung clinic]*

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15 231 Variation in pain management practice

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18 232 There was variation in when and how HCPs approached cancer pain management
19
20 233 during consultations, related to time, rapport and location. Participants stated pain
21
22 234 management conversations required *“empathy and sensitivity”* – [P001], yet
23
24 235 developing the necessary rapport took time. Participants suggested patients received
25
26 236 pain assessments at different points in a care journey, i.e. initial or follow-up
27
28 237 consultations. HCPs acknowledged the extent to which pain management was
29
30 238 approached and communicated to patients depended on specific diagnosis groups
31
32 239 with differing levels of associated pain. If HCPs were seeing a *“new cancer patient*
33
34 240 *with less pain”- [P008]* consultants prioritised other areas of the patient’s care (i.e.
35
36 241 arranging treatment, discussing patient concerns):

37
38
39 242 *“If I’m consenting them for radiotherapy a lot of them won’t really be having any*
40
41 243 *pain, so you know I’ll ask, and if they’re saying no, then that’s fine” P008*
42
43 244 *[Registrar, Lung clinic]*

44
45
46 245 HCPs suggested discussing other areas of cancer-related care meant opportunities
47
48 246 for an in-depth, detailed pain assessment were potentially lost. For patients with
49
50 247 specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment

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4 248 identified pain management as a priority. HCPs made clinical judgements on the
5
6 249 extent and timing of pain management discussions. This included recognising when
7
8
9 250 external factors could potentially exacerbate pain, for example, “*frailty in older patients,*
10
11 251 *comorbidities or smoking*”- [P003].

12
13
14 252 “*Some patients are straightforward. Whereas a lot of lung patients have been*
15
16
17 253 *heavy smokers. They've got COPD and ischemic heart disease...where you*
18
19
20 254 *really have got to get into conversations about pain in a big way*” P003
21
22 255 *[Consultant, haematology clinic]*

23
24
25 256 HCPs suggested follow-up consultations were variable and depended on the care
26
27
28 257 needs and severity of the patient’s cancer. For patients with advanced cancer that
29
30
31 258 were seen weekly it could be easier to monitor and explore pain. HCPs described
32
33 259 difficulties with building rapport to explore pain when appointments were infrequent
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35
36 260 and patients did not see the same HCP at follow-up appointments.

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42 262 Remote consulting impacted pain assessment

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45 263 Management of oncology outpatient care has changed since COVID-19 pandemic and
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48 264 more consultations are conducted remotely. HCPs described advantages to remote
49
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51 265 consulting as it enabled easier, more frequent contact with patients and supported
52
53 266 continuity of care:

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56 267 “*We would, you know put that as part of our diary for the following day to call*
57
58
59 268 *back and see. Make sure that it was working*” P005 [CNS, upper GI clinic]

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4 269 However, some HCPs found remote consulting prevented non-verbal observations of
5
6 270 pain and experienced clinicians recognised that this impeded their ability to do a
7
8
9 271 detailed pain assessment:

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11
12 272 *“And saying to a patient, is it the lumbar region? Why would they know that”*

13
14
15 273 *P004 [CNS, haematology clinic]*

16
17
18 274 HCPs described a risk of patients misattributing cancer-related pain for side effects
19
20 275 and symptoms during remote consultations, making it challenging to provide
21
22
23 276 appropriate treatment. HCPs had to *“take [it] on the patient’s own word”-[P002]* feeling
24
25
26 277 there was *“no other option”- [P002]*. Some HCPs felt pain assessments began from
27
28 278 observations of non-verbal cues when *“they call the patient from the waiting room”-*
29
30
31 279 *P011*, which was not possible in telephone consultations. This contributed to the
32
33
34 280 overall judgement of the patient’s pain:

35
36
37 281 *“You notice whether they’re in a wheelchair, how they’re able to get out of their*

38
39 282 *chair, whether they can walk down the corridor as fast or slower than you can”*

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42 283 *P018 [Consultant, breast clinic].*

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49 285 Healthcare professional’s roles and responsibilities

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51 286 There was a diffusion of responsibility when HCPs discussed pain management. Due
52
53
54 287 to other community-based HCPs (i.e. GPs, palliative care teams) also being able to
55
56
57 288 monitor and manage a patient’s pain, some oncologists in secondary care felt it was
58
59 289 not their responsibility therefore did not engage in detailed pain conversations, e.g. it
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4 290 was a “community palliative nurse’s job to manage pain”- [P003]. However, HCPs did
5
6 291 not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss
7
8
9 292 this pain with the patient’s community teams and thus developed a self-management
10
11 293 plan for the patient to follow:

12
13
14 294 *“You’re thinking about, well, the patient could be suffering tonight. You know, I*
15
16
17 295 *can maybe address some of these issues now” P003 [Consultant, haematology*
18
19
20 296 *clinic].*

21
22
23 297 Some HCPs described how patients needed to take “ownership”-[P014] and
24
25 298 “responsibility”-[P003] to disclose if they were experiencing pain because patients
26
27
28 299 often withheld the extent of their pain due to “fears of bothering the clinician”- [P008]
29
30
31 300 making it more challenging to accurately assess and manage. In some instances,
32
33
34 301 HCPs felt patients needed to provide honest opinions to support a thorough
35
36 302 assessment and avoid uncontrolled pain:

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38
39 303 *“You know autonomy to the patient and responsibility to the patient to tell you if*
40
41
42 304 *there’s a problem you know” P014 [Registrar, upper GI clinic]*

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307 **Continuity of care following oncology outpatient consultations**

308 Participants indicated continuity of care for pain management was facilitated by CNS,
309 relationships between oncology HCPs and supportive services (i.e. palliative care

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4 310 teams, pain management services), re-assessment and monitoring of cancer pain
5
6 311 between primary and secondary care and self-management plans to manage cancer
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9 312 pain at home.

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12 313 Utilisation of outpatient oncology CNS

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14 314 Most registrars and consultants entrusted CNS with following up patients and
15
16
17 315 providing pain management support beyond their initial consultation with an
18
19
20 316 oncologist. This was a component of the CNS role to undertake follow-up remote
21
22
23 317 consultations (i.e. telephone or video call) including the re-assessment of pain and
24
25 318 other symptoms:

26
27
28 319 *"I have the support of CNSs, it will be within days [referring to follow-up calls],*
29
30 320 *you know hopefully within a week then I have somebody else checking in on*
31
32
33 321 *them as to whether medication levels need increasing" P007 [Consultant,*
34
35 322 *prostate clinic].*

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39 323 Consultants reflected on a CNS ability to build rapport with patients and provide a
40
41
42 324 personalised continuity of care making patients more willing to openly disclose their
43
44
45 325 pain. One example showed CNS identifying problematic pain with a patient and
46
47
48 326 escalating this to the consultant to be explored further at follow-up consultations so
49
50 327 changes can be made to medication:

51
52
53 328 *"If there's a note or a, verbal reminder [referring to a nurse providing notes to a*
54
55 329 *consultant about a patient's pain]. Actually, they have had some problems with*

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4 330 *pain or this particular issue then that definitely works well” P011 [Consultant,*
5
6 331 *haematology clinic].*
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8

9 332 If there were little or no CNS staff available to support the management of pain
10
11 333 following consultations with an oncologist, participants suggested it placed strain on
12
13 334 other HCPs to fulfil this role. Consultants and registrars expressed concerns for having
14
15 335 *“triple booked clinics”- [P003] and calling patients “three hours after their appointment*
16
17 336 *time”-[P003] when there were no CNS staff to support clinics.*
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26 338 Integration of supportive services

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29 339 Relationships between supportive services (i.e. palliative care, community nursing
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31 340 teams and pain team) and oncology HCPs were essential to cancer pain management.
32
33 341 While HCPs expressed confidence in their ability to identify and treat cancer pain,
34
35 342 there were circumstances where HCPs described *“reaching their limits”- [P012] on*
36
37 343 *providing recommendations on complex opioid medication and required specialist*
38
39 344 *support:*
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45 345 *“we’re used to drugs like Gabapentin, Amitriptyline but when patients are still*
46
47 346 *having pain, that’s when you need help and we’re lucky, we can ring the palliative*
48
49 347 *care team and there is somebody that can review the patient...usually you can get*
50
51 348 *access to that specialist advice if you need”.P012 [Consultant, lung clinic]*
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55
56 349 In some cases, the level of responsibility and expertise the clinician felt they had over
57
58 350 managing a patient’s pain (i.e. pain was important part of consultation discussions)
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4 351 influenced whether a patient would be referred to another team or managed by
5
6 352 themselves. Data suggested optimal pain management often involved HCPs
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9 353 identifying and monitoring pain whilst utilising supportive services for advice and
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11 354 guidance to develop appropriate treatment pathways.
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18 356 Reassessment and monitoring of cancer pain between primary and secondary
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20 357 care

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23 358 Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make
24
25 359 amendments to medication more frequently. In OS a clinicians' opportunity to re-
26
27 360 assess and monitor cancer pain was constrained by the frequency of appointments on
28
29 361 weekly, monthly or greater basis. Some oncology OS support patients from "*large*
30
31 362 *geographical areas*"-[P005] therefore patients might not return for consistent follow-up
32
33 363 appointments. Participants reported this made it difficult for HCPs to provide continuity
34
35 364 of care and put more dependency on managing cancer pain between primary and
36
37 365 secondary care:
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43

44 366 *"What we don't have a mechanism like we do on the ward... We simply don't*
45
46 367 *have that contact, so we are next seeing the patients usually in three or six*
47
48 368 *weeks' time. So the pattern of medical interaction it simply doesn't map on to*
49
50 369 *pain relief"* P018 [Consultant, breast clinic]
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56 370 HCPs emphasised pain management decisions needed to be made in line with the
57
58 371 patient's needs and their ability to conveniently access primary care. As a result of
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4 372 this, patients and HCPs often had to *“rely on the GPs to issue drugs and escalate pain*
5
6 373 *control”- [P014].*
7
8

9 374 *“We would also encourage patients to seek support from the GP and there will*
10
11
12 375 *come a time when it's beyond our scope” P005 [CNS, upper GI clinic]*
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18 377 Providing patients with supported self-management plans to manage cancer
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21 378 pain at home
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24 379 Due to the challenges with assessment and re-assessment in OS, some HCPs
25
26 380 suggested providing a *“safety net”-[P016]*for the patient was a crucial aspect to ensure
27
28
29 381 cancer pain was adequately reviewed. This involved developing a strategy so a patient
30
31 382 knew what to do if the pain relief was not effective or if they were still experiencing
32
33
34 383 severe pain:
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36

37 384 *“I want you to see how those go and then perhaps give them a time period, so this*
38
39
40 385 *is gonna take a few days for this to start to work better. If things are not any better,*
41
42
43 386 *then to call us back” P016 [Consultant, haematology clinic]*
44

45 387 Some HCPs provided patients with documentation that included information on how,
46
47
48 388 when and what medication to take, as well as contact information for the OS and out-
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51 389 of-hours services. This was one-way HCPs ensured patients were supported to self-
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53 390 manage cancer pain at home:
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391 *“If there is anything of concern there is a number that you can call 24 hours a*
392 *day, 7 days a week, 365 days a year and then we can see them on the acute*
393 *unit and take it from there” P006 [Registrar, urology clinic]*

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4 394 **Discussion**

5
6 395 We found an unstructured and variable approach to pain management affected
7
8 396 multiple components of a patient's outpatient cancer care. Firstly, HCPs used clinical
9
10
11 397 judgement in place of a structured assessment to manage a patient's pain. This
12
13
14 398 explains why HCPs might not use pre-existing guidelines and tools that have been
15
16 399 published (6, 8). Research has highlighted disadvantages to using pain assessment
17
18
19 400 tools, such as oversimplification of the multi-dimensional pain experience and not an
20
21
22 401 appropriate reflection of a patient's pain (19). Pain management tools can be efficient
23
24
25 402 especially when HCPs have limited time or when pain assessments are combined with
26
27 403 an individualised assessment to fully understand how pain is affecting the patient
28
29
30 404 physically, psychologically, socially and culturally.

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32
33 405 Our data show that pain management in oncology outpatient services was influenced
34
35 406 by variation in HCPs' expectation of responsibility for pain management; i.e. it was
36
37
38 407 often considered to be someone else or another services' responsibility. This diffusion
39
40
41 408 of responsibility is well reported in healthcare settings and is known to lead to
42
43
44 409 underperformance of clinical activities and fragmented care in circumstances of
45
46 410 shared accountability (20) Fallon et al. (2018) showed that when structured pain
47
48
49 411 assessment processes are implemented within routine clinical care, this leads to a
50
51 412 more consistent approach to pain management, a reduction in the diffusion of
52
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54 413 responsibility and improved pain outcomes for cancer patients (11).

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4 414 Our data showed variation across the roles and responsibilities of HCPs supporting
5
6 415 the continuity of pain management. Oncology outpatient literature suggests some
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8
9 416 HCPs perceived their primary duty was to provide patients with their disease status
10
11 417 and have conversations around treatment (21). However, our data shows that HCPs
12
13
14 418 who expressed clinical responsibility around pain management were inclined to
15
16 419 develop self-management plans to support patients to manage cancer pain at home.
17
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19
20 420 This study aimed to describe current pain management and thus the interview topic
21
22 421 guide was not developed to explore nuances of self-management practices.
23
24
25 422 However, we know from previous studies there is variation in self-management
26
27 423 approaches (22). In OS, development of self-management support for patients is
28
29 424 crucial to a continuity of care. This includes providing elements of educational
30
31 425 interventions to facilitate problem solving and adequate decision-making skills and
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33 426 tailoring recommendations to the individual's situation and defining goals with action
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35 427 plans (22). By developing supportive plans, it ensures patients understand what to do
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38 428 if pain escalates or becomes unmanageable. Subsequently, it could encourage
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41 429 patients to initiate re-assessment of their pain at primary and secondary care services.
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46 430 We found system-level challenges impacted the extent to which pain was explored
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48 431 with patients and monitored by outpatient HCPs. Exacerbated by the impact of the
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50 432 COVID-19 pandemic, clinics are often over-booked, short staffed, and have long
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52 433 waiting lists (15). In addition, our data show that the complexity surrounding the
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55 434 interface between primary and secondary care and challenges with integration of
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4 435 multi-disciplinary teams meant continuity of care, in particular re-assessment and
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6 436 monitoring of pain, was difficult as patients were referred back to primary or community
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9 437 care teams.

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12 438 Oncologists found it difficult to build rapport with patients that might not return to
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14 439 outpatient appointments and felt they had to prioritise topics of care with the limited
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17 440 time they had. Consultations take a patient-centred approach that prioritises care
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20 441 practices that are responsive to a patient's preferences and values and thus not
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22 442 focusing on pain management may be appropriate for some patients. However, this
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25 443 study and previous research has highlighted patients can often be reluctant to express
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28 444 their concerns and preferences without prompting (13). This suggests the
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30 445 development of rapport with patients is essential to gain full understanding of a
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33 446 patient's care needs. We found CNS had more opportunities to build rapport and have
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36 447 discussions about pain with patients. However, in line with previous studies (14)
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38 448 opportunities for pain management discussions are often missed if there are nurses
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41 449 with less experience and confidence to conduct pain assessments. Recommendations
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44 450 from this study highlight the benefit of providing training for HCPs to support pain
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46 451 management conversations and embedding this within routine clinical practice.

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49 452 Oncology literature has highlighted the benefits for the use of remote consultations in
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52 453 cancer pain management, where it is used appropriately. For example, reduction in
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55 454 pain severity scores, cost-effective, improved accessibility for patients to receive HCP
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57 455 advice and treatment of symptoms and aided monitoring and re-assessment of
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4 456 symptoms (23, 24). We found adaptations to pain assessments for remote care
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6 457 impeded experienced HCPs to do a detailed thorough pain assessment, especially if
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9 458 not Audio Visual (AV) facilitated. HCPs become experts in their field through
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11 459 knowledge, skill, training and experiential learning (25). Since COVID-19 the increased
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14 460 use of remote consultations has meant HCPs have to spend more time doing pain
15
16 461 assessments remotely. However, due to a lack of experiential learning for conducting
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19 462 pain assessments through remote consultations, this potentially made even
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22 463 experienced HCPs feel like a novice. This coincides with the novice to expert theory
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24 464 (25). Similarly, for those with less experience a change in mode-of-consulting could
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27 465 further impede thorough pain assessments for patients. Without additional support and
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30 466 structured guidance on how to conduct remote consultations there is a risk that
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32 467 patients' pain will not be appropriately managed and key components of a detailed
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35 468 pain assessment potentially missed. Previous research has shown even when pain
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38 469 assessments are standardised and detailed, only modest improvements in pain for
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40 470 patients with cancer are observed, largely because of low delivery fidelity and poor
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43 471 implementation (6). However, Fallon et al. (2018) demonstrated that when
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45 472 standardised pain assessment processes are integrated within routine clinical practice
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47
48 473 at the level of the service (rather than at an individual clinician level) this leads to
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51 474 greater improvements in pain outcomes for patients and more appropriate analgesic
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53 475 prescribing. This suggests an in-depth implementation plan at service-level would be
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55
56 476 crucial to the success of a structured pain management intervention.

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4 478 Strengths and limitations
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6 479 A structured sampling framework was developed by the research team which may
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8 480 have resulted in potential bias. However, this approach provided a heterogeneous
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11 481 sample of staff roles, seniority and clinical speciality that gave a greater understanding
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14 482 to the management of different types of pain prevalence patients experienced. All
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16 483 participants were from Northern England; therefore, the study's findings may not be
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19 484 generalisable to other regional oncology outpatient settings or international healthcare
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22 485 systems. One limitation is related to our recruitment strategy (i.e. self-referral sampling
23
24 486 after HCPs received an information pack); due to the nature of the research aims (i.e.
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26
27 487 pain management in oncology) participants with strong negative or positive views may
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29
30 488 have been more likely to agree to participate. However, the themes identified from the
31
32 489 data indicated broad perspectives of pain management processes and experience, so
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34
35 490 it is unlikely that we have sampled an exclusively polarised group of participants.
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41 492 Implications of clinical research and practice
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43
44 493 Faculty of Pain Medicine Core standards for cancer pain management (12) state all
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46 494 patients should receive a pain assessment at each encounter with an oncology
47
48
49 495 clinician that includes exploration of intensity, mechanisms, aetiology and impact.
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52 496 Evidence from clinical trials show that standardising pain assessment in oncology
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54 497 outpatient clinics leads to improvements in patients' pain and quality of life (11). This
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57 498 research recommends the implementation of a structured routine pain assessment
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4 499 that minimises the risk of diffusion of responsibility and encourages HCPs to
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6 500 incorporate the most crucial components of a pain assessment into patient
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9 501 consultations (i.e. exploration of intensity, mechanisms, aetiology and impact).
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11 502 Secondly, at a service level, uncontrolled cancer pain remains the most common
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13
14 503 reason for contacting GP out-of-hours service (10). Implementing a structured pain
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16 504 assessment within oncology OS would encourage patients to report pain earlier,
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19 505 enabling HCPs to manage cancer pain earlier, reducing the burden on GP out-of-hours
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22 506 service, and minimising the risk of patients living with undertreated cancer pain.
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25 507 Conclusion

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27
28 508 This study demonstrates a variable and unstructured approach to pain management
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30 509 affected multiple components of a patient's outpatient cancer care. We recommend
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33 510 the need for a cancer pain management intervention that standardises pain
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36 511 assessments in oncology OS, which is implemented at the level of the service. This
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38 512 will ensure each patient receives the same detailed evaluation of cancer pain and is
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41 513 provided with a self-management strategy that facilitates pain management beyond
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43 514 consultations.
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49 516 List of abbreviations

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53 517 HCP – Healthcare Professionals

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56 518 OS – Outpatient Services
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4 519 CNS – Clinical Nurse Specialist
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7 520 Upper GI - Upper Gastrointestinal tract
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10 521 NHS – National Health Service
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13 522 AV – Audio Visual
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20 524 Declarations
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22
23 525 **Ethical approval and consent to participate**
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25
26 526 Ethical approval was obtained by University of Leeds, Faculty of Medicine Research
27

28
29 527 Ethics Committee and Health Research Authority (21/HRA/5245). Approvals were
30

31
32 528 also obtained at each NHS trust.
33

34
35 529 **Consent for publication**
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37
38 530 Not applicable
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41 531 **Availability of data and materials**
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43
44 532 Not applicable
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47 533 **Competing interest's statement**
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49
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51

52
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54

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3 **537 Authors' contribution**

4
5
6
7 **538** MM is the chief investigator for this study; he conceived the project, led the design and

8
9 **539** writing of the study protocol, facilitated data analysis and drafting of this manuscript.

10
11
12 **540** Methodology (OR, MM). Project administration (OR, MM).

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14
15 **541** OR wrote the study protocol, including drafting the topic guide, completed data

16
17 **542** curation, data collection and transcribed interviews. OR led the data analysis and

18
19 **543** interpretation of the data. Review of interpretation of the data and analysis was done

20
21 **544** by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. Writing-review

22
23 **545** and editing (OR, MM, SR). All authors (OR, SP, KF, NC, MF, SR, CM, EB, DS, AH,

24
25 **546** SH, MM) contributed to manuscript revision, read and approved the submitted and

26
27 **547** revised version.

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34 **548**

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42
43
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45
46
47 **552** NHS Trusts: Leeds Teaching Hospitals, Hull University Teaching Hospital, Sheffield

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49
50 **553** University Teaching Hospital

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53 **554**

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For peer review only



Interview topic guide

❖ **Professional Background**

(role, experience, knowledge/training in pain assessment and management, contact with advanced cancer patients)

❖ **Experiences of conducting pain assessments to support to people with advanced cancer**

- Assessment
 - Basic: pain intensity and interference
 - Detailed: underlying aetiology and pain mechanism, linked analgesic prescribing
- Decision-making
- Access to cancer pain management guidelines
- Providing cancer treatments and care
- Communication between oncology and patient
- Follow-up contact between patient and hcp

❖ **Identifying triggers for pain assessment**

- *what factors would lead doctor or nurse to undertake a pain assessment*

❖ **Specific examples of cancer pain assessments that have been conducted**

- *Talk us through how pain is assessed and managed in practice*

❖ **Examples of existing tools used in everyday pain assessment practice**

- *What works with this pain assessment tool or needs improving?*
- *Any challenges with using the tools in everyday practice?*

❖ **Anything that is difficult when people have advanced cancer to assess and manage their pain?**

❖ **Anything that works well?**

N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.



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❖ ***Suggestions for how pain assessment could be improved for people with advanced cancer?***

14 To ask participants that have insight and knowledge into existing clinical pathways:

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❖ ***Implementing routine pain assessment within existing clinical pathways***

- Describe how a new treatment or procedure is currently integrated into an outpatient service?
- Who is responsible for making sure everyone is trained and using the new treatment or procedure?
- How can routine pain assessments be integrated into existing clinical pathways in your oncology outpatient service?
- Explain what these improvements might make?
- Any potential system level challenges?

❖ ***Anything you would like to add?***

N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.



SRQR 21-point checklist

No.	Topic	Completed	Page no.
1.	Title	<input checked="" type="checkbox"/>	1
2.	Abstract	<input checked="" type="checkbox"/>	2
3	Problem formulation	<input checked="" type="checkbox"/>	3
4.	Purpose or research question	<input checked="" type="checkbox"/>	4
5.	Qualitative approach	<input checked="" type="checkbox"/>	4
6.	Research characteristics and reflexivity	<input checked="" type="checkbox"/>	5
7.	Context	<input checked="" type="checkbox"/>	4
8.	Sampling strategy	<input checked="" type="checkbox"/>	4
9.	Ethical Issues	<input checked="" type="checkbox"/>	5/18
10.	Data collection methods	<input checked="" type="checkbox"/>	5
11.	Data collection instruments and technologies	<input checked="" type="checkbox"/>	5
12.	Units of study	<input checked="" type="checkbox"/>	6
13.	Data processing	<input checked="" type="checkbox"/>	5
14.	Data analysis	<input checked="" type="checkbox"/>	6/7
15.	Techniques to enhance trustworthiness	<input checked="" type="checkbox"/>	5
16.	Synthesis and interpretation	<input checked="" type="checkbox"/>	5
17.	Links to empirical data	<input checked="" type="checkbox"/>	8-13
18.	Integration with prior work, implications, and contribution to field	<input checked="" type="checkbox"/>	14-16
19.	Limitations	<input checked="" type="checkbox"/>	16
20.	Conflict of interest	<input checked="" type="checkbox"/>	18
21.	Funding	<input checked="" type="checkbox"/>	18