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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 with patients; and, (5) continuity of care for pain management was constrained by the integration of multi-disciplinary teams.

Conclusions: These data demonstrate HCP cancer pain management practices varied and were unstructured. Recommendations are made for a standardised cancer pain management intervention: (1) detailed evaluation of pain with a tailored self-management strategy; (2) implementation of a structured pain assessment that supports remote consultations, (3) pain assessment tool that can support both experienced and less experienced clinicians. These findings will inform the development of a cancer pain management tool to integrate within routine oncology OS.

Strengths and Limitations of this study

- To our knowledge, this study is the first to qualitative study that has explored in-depth cancer pain management processes and experiences in oncology outpatient settings from the perspective of healthcare professionals.

- A structured sampling framework was used to ensure a heterogenous sample of roles, seniority and clinical speciality were recruited to the study, this enabled a detailed understanding to different types of pain prevalence patients experienced.

- Our methodological approach to recruitment may have led to bias, as participants with strong negative or positive views may have been more likely to agree to participate to the study.

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

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

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 were conducted through telephone and video calling software to suit the participants. Verbal consent was obtained by OR at the beginning of the interview. The consent audio was recorded and stored separately to the main interview recording.

Patient and Public Involvement

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

Data collection

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

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	
Healthcare professionals (n=20)	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
Cancer sub-speciality area	
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.

	Remote consulting impact on pain assessment. HCPs felt remote consultations impeded even experienced HCPs ability to do a detailed pain assessment.
	HCP's roles and responsibilities. Varied responsibility felt by HCPs to manage cancer pain.
Continuity of care following oncology consultations	**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.
	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.
	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.
	Self-management plans to manage cancer pain at home. HCPs created self-

	management plans for patient to ensure their cancer pain was adequately reviewed.

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

> *"Thoracic cancers I'd always ask about chest pain specifically and risk of pain or swelling outside of the chest and with gynaecological cancers I'd say "have you had any abdominal pain or bloating" P008 [Registrar, lung clinic]*

Variation in pain management practice

There was variation in when and how HCPs approached cancer pain management during consultations, related to time, rapport and location. Participants stated pain management conversations required "*empathy and sensitivity"* – [P001], yet developing the necessary rapport took time. Participants suggested patients received pain assessments at different points in a care journey, i.e. initial or follow-up consultations. HCPs acknowledged the extent to which pain management was approached and communicated to patients depended on specific diagnosis groups with differing levels of associated pain. If HCPs were seeing a *"new cancer patient with less pain"- [P008]* consultants prioritised other areas of the patient's care (i.e. arranging treatment, discussing patient concerns):

> *"If I'm consenting them for radiotherapy a lot of them won't really be having any pain, so you know I'll ask, and if they're saying no, then that's fine" P008 [Registrar, Lung clinic]*

HCPs suggested discussing other areas of cancer-related care meant opportunities for an in-depth, detailed pain assessment were potentially lost. For patients with specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment identified pain management as a priority. HCPs made clinical judgements on the extent and timing of pain management discussions. This included recognising when external factors could potentially exacerbate pain, for example, "*frailty in older patients, comorbidities or smoking*"*- [P003]*:

> *"Some patients are straightforward. Whereas a lot of lung patients have been heavy smokers. They've got COPD and ischemic heart disease…where you really have got to get into conversations about pain in a big way" P003 [Consultant, haematology clinic]*

HCPs suggested follow-up consultations were variable and depended on the care needs and severity of the patient's cancer. For patients with advanced cancer that were seen weekly it could be easier to monitor and explore pain. HCPs described difficulties with building rapport to explore pain when appointments were infrequent and patients did not see the same HCP at follow-up appointments.

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:

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

Healthcare professional's roles and responsibilities

There was a diffusion of responsibility when HCPs discussed pain management. Due to other community-based HCPs (i.e. GPs, palliative care teams) also being able to monitor and manage a patient's pain, some oncologists in secondary care felt it was not their responsibility therefore did not engage in detailed pain conversations, e.g. it was a "*community palliative nurse's job to manage pain"- [P003].* However, HCPs did not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss this pain with the patient's community teams and thus developed a self-management plan for the patient to follow:

> *"You're thinking about, well, the patient could be suffering tonight. You know, I can maybe address some of these issues now" P003 [Consultant, haematology clinic].*

Some HCPs described how patients needed to take *"ownership"-[P014]* and *"responsibility"-[P003]* to disclose if they were experiencing pain because patients often withheld the extent of their pain due to *"fears of bothering the clinician"-* [P008] making it more challenging to accurately assess and manage. In some instances, HCPs felt patients needed to provide honest opinions to support a thorough assessment and avoid uncontrolled pain:

> *"You know autonomy to the patient and responsibility to the patient to tell you if there's a problem you know" P014 [Registrar, upper GI clinic]*

Continuity of care following outpatient consultations

Participants indicated continuity of care for pain management was facilitated by CNS, relationships between oncology HCPs and supportive services (i.e. palliative care teams, pain management services), re-assessment and monitoring of cancer pain between primary and secondary care and self-management plans to manage cancer pain at home.

Utilisation of outpatient oncology CNS

Most registrars and consultants entrusted CNS with following up patients and providing pain management support beyond their initial consultation with an oncologist. This was a component of the CNS role to undertake follow-up remote consultations (i.e. telephone or video call) including the re-assessment of pain and other symptoms:

> *"I have the support of CNSs, it will be within days [referring to follow-up calls], you know hopefully within a week then I have somebody else checking in on*

> *them as to whether medication levels need increasing" P007 [Consultant, prostate clinic].*

Consultants reflected on a CNS ability to build rapport with patients and provide a personalised continuity of care making patients more willing to openly disclose their pain. One example showed CNS identifying problematic pain with a patient and escalating this to the consultant to be explored further at follow-up consultations so changes can be made to medication:

> *"If there's a note or a, verbal reminder [referring to a nurse providing notes to a consultant about a patient's pain]. Actually, they have had some problems with pain or this particular issue then that definitely works well" P011 [Consultant, haematology clinic].*

If there were little or no CNS staff available to support the management of pain following consultations with an oncologist, participants suggested it placed strain on other HCPs to fulfil this role. Consultants and registrars expressed concerns for having *"triple booked clinics"- [P003]* and calling patients *"three hours after their appointment time"-[P003]* when there were no CNS staff to support clinics.

Integration of supportive services

Relationships between supportive services (i.e. palliative care, community nursing teams and pain team) and oncology HCPs were essential to cancer pain management. While HCPs expressed confidence in their ability to identify and treat cancer pain, there were circumstances where HCPs described *“reaching their limits”- [P012]* on providing recommendations on complex opioid medication and required specialist support:

> *”we’re used to drugs like Gabapentin, Amitriptyline but when patients are still having pain, that’s when you need help and we’re lucky, we can ring the palliative care team and there is somebody that can review the patient…usually you can get access to that specialist advice if you need”.P012 [Consultant, lung clinic]*

In some cases, the level of responsibility and expertise the clinician felt they had over managing a patient’s pain (i.e. pain was important part of consultation discussions) influenced whether a patient would be referred to another team or managed by themselves. Data suggested optimal pain management often involved HCPs identifying and monitoring pain whilst utilising supportive services for advice and guidance to develop appropriate treatment pathways.

Re-assessment and monitoring of cancer pain between primary and secondary care

Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make amendments to medication more frequently. In OS a clinicians’ opportunity to re-assess and monitor cancer pain was constrained by the frequency of appointments on weekly, monthly or greater basis. Some oncology OS support patients from *“large geographical areas”-[P005]* therefore patients might not return for consistent follow-up appointments. Participants reported this made it difficult for HCPs to provide continuity of care and put more dependency on managing cancer pain between primary and secondary care:

> *"What we don't have a mechanism like we do on the ward…We simply don't have that contact, so we are next seeing the patients usually in three or six weeks' time. So the pattern of medical interaction it simply doesn't map on to pain relief" P018 [Consultant, breast clinic]*

HCPs emphasised pain management decisions needed to be made in line with the patient's needs and their ability to conveniently access primary care. As a result of this, patients and HCPs often had to *"rely on the GPs to issue drugs and escalate pain control"- [P014]*:

> *"We would also encourage patients to seek support from the GP and there will come a time when it's beyond our scope" P005 [CNS, upper GI clinic]*

Self-management plans to manage cancer pain at home

Due to the challenges with assessment and re-assessment in OS, some HCPs suggested providing a "*safety net*"*-[P016]* for the patient was a crucial aspect to ensure cancer pain was adequately reviewed. This involved developing a strategy so a patient knew what to do if the pain relief was not effective or if they were still experiencing severe pain:

> *"I want you to see how those go and then perhaps give them a time period, so this is gonna take a few days for this to start to work better. If things are not any better, then to call us back" P016 [Consultant, haematology clinic]*

Some HCPs provided patients with documentation that included information on how, when and what medication to take, as well as contact information for the OS and out-of-hours services. This was one-way HCPs ensured patients were supported to self-manage cancer pain at home:

> *"If there is anything of concern there is a number that you can call 24 hours a day, 7 days a week, 365 days a year and then we can see them on the acute unit and take it from there" P006 [Registrar, urology clinic]*

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 pain management were inclined to develop self-management plans to support patients to manage cancer pain at home.

This study aimed to describe current pain management and thus the interview topic guide was not developed to explored nuances of self-management practices. However, we know from previous studies there is variation in self-management approaches (19). In OS, development of self-management support for patients is crucial to a continuity of care. This includes providing elements of educational interventions to facilitate problem solving and adequate decision-making skills and tailoring recommendations to the individual's situation and defining goals with action plans (19). By developing supportive plans, it ensures patients understand what to do if pain escalates or becomes unmanageable. Subsequently, it could encourage patients to initiate re-assessment of their pain at primary and secondary care services.

We found system-level challenges impacted the extent to which pain was explored with patients and monitored by outpatient HCPs. Exacerbated by the impact of the COVID-19 pandemic, clinics are often over-booked, short staffed, and have long waiting lists (13). In addition, our data show that the complexity surrounding the interface between primary and secondary care and challenges with integration of multi-disciplinary teams meant continuity of care, in particular re-assessment and monitoring of pain, was difficult as patients were referred back to primary or community care teams.

Oncologists found it difficult to build rapport with patients that might not return to outpatient appointments and felt they had to prioritise topics of care with the limited time they had. Consultations take a patient-centred approach that prioritises care practices that are responsive to a patient's preferences and values and thus not focusing on pain management may be appropriate for some patients. However, this study and previous research has highlighted patients can often be reluctant to express their concerns and preferences without prompting (9). This suggests the development of rapport with patients is essential to gain full understanding of a patient's care needs. We found CNS had more opportunities to build rapport and have discussions about pain with patients. However, in line with previous studies (12) opportunities for pain management discussions are often missed if there are nurses with less experience and confidence to conduct pain assessments. Recommendations from this study highlight the benefit of providing training for HCPs to support pain management conversations and embedding this within routine clinical practice.

Oncology literature has highlighted the benefits for the use of remote consultations in cancer pain management, where it is used appropriately. For example, reduction in pain severity scores, cost-effective, improved accessibility for patients to receive HCP advice and treatment of symptoms and aided monitoring and re-assessment of symptoms (20, 21). We found adaptations to pain assessments for remote care impeded experienced HCPs to do a detailed thorough pain assessment, especially if not Audio Visual (AV) facilitated. HCPs become experts in their field through knowledge, skill, training and experiential learning (22). Since COVID-19 the increased use of remote consultations has meant HCPs have to spend more time doing pain assessments remotely. However, due to a lack of experiential learning for conducting pain assessments through remote consultations, this potentially made even experienced HCPs feel like a novice. This coincides with the novice to expert theory (22). Similarly, for those with less experience a change in mode-of-consulting could further impede thorough pain assessments for patients. Without additional support and structured guidance on how to conduct remote consultations there is a risk that patients' pain will not be appropriately managed and key components of a detailed pain assessment potentially missed. Previous research has shown even when pain assessments are standardised and detailed, only modest improvements in pain for patients with cancer are observed, largely because of low delivery fidelity and poor implementation (10). However, Fallon et al. (2018) demonstrated that when standardised pain assessment processes are integrated within routine clinical practice at the level of the service (rather than at an individual clinician level) this leads to greater improvements in pain outcomes for patients and more appropriate analgesic prescribing. This suggests an in-depth implementation plan at service-level would be crucial to the success of a structured pain management intervention.

Strengths and limitations

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

Implications of clinical research and practice

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

Conclusion

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

List of abbreviations

HCP – Healthcare Professionals

OS – Outpatient Services

CNS – Clinical Nurse Specialist

Upper GI - Upper Gastrointestinal tract

NHS – National Health Service

AV – Audio Visual

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

MM is the chief investigator for this study; he conceived the project, led the design and writing of the study protocol, facilitated data analysis and drafting of this manuscript.

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

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Yorkshire Cancer Research

UNIVERSITY OF LEEDS

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.

Interview topic guide Version 0.1 06.10.2021 IRAS: 305397

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

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

❖ *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	☒	1
2.	Abstract	☒	2
3	Problem formulation	☒	3
4.	Purpose or research question	☒	4
5.	Qualitative approach	☒	4
6.	Research characteristics and reflexivity	☒	5
7.	Context	☒	4
8.	Sampling strategy	☒	4
9.	Ethical Issues	☒	5/18
10.	Data collection methods	☒	5
11.	Data collection instruments and technologies	☒	5
12.	Units of study	☒	6
13.	Data processing	☒	5
14.	Data analysis	☒	6/7
15.	Techniques to enhance trustworthiness	☒	5
16.	Synthesis and interpretation	☒	5
17.	Links to empirical data	☒	8-13
18.	Integration with prior work, implications, and contribution to field	☒	14-16
19.	Limitations	☒	16
20.	Conflict of interest	☒	18
21.	Funding	☒	18

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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 with patients; and, (5) continuity of care for pain management was constrained by the integration of multi-disciplinary teams.

Conclusions: These data demonstrate HCP cancer pain management practices varied and were unstructured. Recommendations are made for a standardised cancer pain management intervention: (1) detailed evaluation of pain with a tailored self-management strategy; (2) implementation of a structured pain assessment that supports remote consultations, (3) pain assessment tool that can support both experienced and less experienced clinicians. These findings will inform the development of a cancer pain management tool to integrate within routine oncology OS.

Strengths and Limitations of this study

- To our knowledge, this is one of the first qualitative studies that has provided a descriptive account of cancer pain management processes and experiences in oncology outpatient settings from the perspective of healthcare professionals.

- A structured sampling framework was used to ensure a heterogeneous sample of roles, seniority and clinical speciality were recruited to the study. This enabled a detailed understanding to different types of pain prevalence patients experienced.

- Our recruitment strategy (i.e. self-referral sampling after receiving an information pack) may have led to bias, as individuals with strong negative or positive views may have been more likely to self-refer and agree to participate to the study.

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).

The underlying pathophysiology of cancer pain is complex; nociceptive, inflammatory, and neuropathic mechanisms exist in concert with psychological and emotional components of chronic pain, making cancer pain challenging to manage clinically (6) (7). Historically, the management of cancer pain has been based on evaluating the subjective intensity of pain (via 0-10 Likert scales) (8) which do not evaluate aetiology, mechanisms or psychological components of pain (9). In addition, the challenging clinical environment within an oncology outpatient department means that cancer pain management is one of many competing priorities that healthcare professionals (HCPs) must manage during a time-limited consultation. 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 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 (10).

When cancer pain is routinely assessed on hospital wards or in outpatient clinics, this improves pain control for patients (11). The UK Faculty of Pain Medicine has published Core Standards for cancer pain management (12) 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 (13). Despite decades of national and international guidelines on cancer pain management (6, 8) inadequate pain assessment continues to be a barrier to good pain control for patients with cancer. Wider oncology literature has suggested HCPs required more educational opportunities for prescribing complex pain relief medications to cancer patients (14).

External factors can also influence effective pain management processes. In the UK, referral to oncology begins in primary care, this is community-based care provided by general practitioners (GPs). Reduced referrals from primary care during the COVID-19 pandemic has led to an increase in the numbers of patients diagnosed with advanced cancer post-pandemic. This has been compounded by staff shortages in oncology OS and increasing levels of sickness absence and burnout in the workforce (15). In the UK, minimal qualitative studies have explored current pain management practices for people with cancer in oncology OS. The aim of this qualitative investigation was to describe cancer pain management practices and clinical care pathways for cancer pain management used by HCPs to understand the barriers and facilitators for standardised pain management in oncology OS.

Methods

Design

Qualitative interview study exploring pain management practices for people with cancer in oncology OS from the perspective of 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 via co-applicant HCPs embedded within the clinical teams, who emailed study information packs (i.e. information sheet, consent form) to their entire clinical teams. Contact information of the research team (OR/MM) was included in study information packs and potentially eligible participants were asked to contact the research team (OR/MM). When potentially eligible participants contacted the research team (OR/MM) the study was discussed in detail, any questions answered, and a date/time arranged for an interview. Interviews were conducted through telephone and video calling software to suit the participants. Verbal consent was obtained by OR at the beginning of the interview. The consent audio was recorded and stored separately to the main interview recording.

Patient and Public Involvement

A patient and public involvement (PPI) group was established at the beginning of the project. Our PPI group included people with personal experiences of managing cancer pain and one former carer. One PPI member was also a grant co-applicant. The PPI group met during the study development phase to contribute to the design and delivery methods. This included providing feedback on the development of study documents and processes. Once data had been collected, transcribed and summarised the PPI group met to provide feedback on the initial themes and sub-themes identified from the data.

Data collection

Interviews were conducted by OR between March 2022 and May 2022. Sample size was determined based on previous qualitative studies conducted in oncology OS (16, 17). Recruitment and analysis continued in tandem until data saturation was reached. An interview topic guide was informed by existing literature and expert input from the research and Patient and Public Involvement group (see additional file 1). Participants were asked about their experiences of cancer pain management in oncology OS. This included exploring current practice, challenges and identifying what could be done to improve how pain is managed. OR and MM held weekly meetings to discuss the interviews and influence of researcher bias on the dataset was documented.

Data analysis

Data analysis was done using Braun and Clark's Thematic Analysis (18). 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; preliminary analyses was undertaken throughout the data collection process and the topic guide was adjusted accordingly to explore existing and new patterns identified within the data. After familiarising themselves with the transcripts, initial coding and development of themes was done by OR, MM and SP. Through a series of data analysis meetings, the initial themes and sub-themes were presented to the wider research team and our PPI group to explore their meaning and significance. During these meetings each theme and sub-theme was described in detail and supporting evidence (codes and quotes) was presented and discussed. Following each data analysis meeting the themes and sub-themes were refined in an iterative process until the themes were agreed. 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	
Healthcare professionals (n=20)	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
Cancer sub-speciality area	
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) *Pain management practices during oncology outpatient consultations* and (2) *delivering continuity of care beyond oncology outpatient 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

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.

Pain management practices during oncology 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 experience influenced 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, several HCPs felt pain scales did not provide a valid representation of a patient's pain because the subjective nature of pain made it *"difficult to apply to numbers"- [P006].* Asking questions associated with the type of cancer, initiated patients to think in-depth about the context, triggers, occurrences and nature of the pain:

> *"Thoracic cancers I'd always ask about chest pain specifically and risk of pain or swelling outside of the chest and with gynaecological cancers I'd say "have you had any abdominal pain or bloating" P008 [Registrar, lung clinic]*

Variation in pain management practice

There was variation in when and how HCPs approached cancer pain management during consultations, related to time, rapport and location. Participants stated pain management conversations required "*empathy and sensitivity"* – [P001], yet developing the necessary rapport took time. Participants suggested patients received pain assessments at different points in a care journey, i.e. initial or follow-up consultations. HCPs acknowledged the extent to which pain management was approached and communicated to patients depended on specific diagnosis groups with differing levels of associated pain. If HCPs were seeing a *"new cancer patient with less pain"- [P008]* consultants prioritised other areas of the patient's care (i.e. arranging treatment, discussing patient concerns):

> *"If I'm consenting them for radiotherapy a lot of them won't really be having any pain, so you know I'll ask, and if they're saying no, then that's fine" P008 [Registrar, Lung clinic]*

HCPs suggested discussing other areas of cancer-related care meant opportunities for an in-depth, detailed pain assessment were potentially lost. For patients with specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment identified pain management as a priority. HCPs made clinical judgements on the extent and timing of pain management discussions. This included recognising when external factors could potentially exacerbate pain, for example, "*frailty in older patients, comorbidities or smoking"- [P003]*:

> *"Some patients are straightforward. Whereas a lot of lung patients have been heavy smokers. They've got COPD and ischemic heart disease…where you really have got to get into conversations about pain in a big way" P003 [Consultant, haematology clinic]*

HCPs suggested follow-up consultations were variable and depended on the care needs and severity of the patient's cancer. For patients with advanced cancer that were seen weekly it could be easier to monitor and explore pain. HCPs described difficulties with building rapport to explore pain when appointments were infrequent and patients did not see the same HCP at follow-up appointments.

Remote consulting impacted 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:

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

Healthcare professional's roles and responsibilities

There was a diffusion of responsibility when HCPs discussed pain management. Due to other community-based HCPs (i.e. GPs, palliative care teams) also being able to monitor and manage a patient's pain, some oncologists in secondary care felt it was not their responsibility therefore did not engage in detailed pain conversations, e.g. it was a “*community palliative nurse’s job to manage pain”- [P003].* However, HCPs did not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss this pain with the patient’s community teams and thus developed a self-management plan for the patient to follow:

> *“You're thinking about, well, the patient could be suffering tonight. You know, I can maybe address some of these issues now” P003 [Consultant, haematology clinic].*

Some HCPs described how patients needed to take *“ownership”-[P014]* and *“responsibility”-[P003]* to disclose if they were experiencing pain because patients often withheld the extent of their pain due to *“fears of bothering the clinician”-* [P008] making it more challenging to accurately assess and manage. In some instances, HCPs felt patients needed to provide honest opinions to support a thorough assessment and avoid uncontrolled pain:

> *“You know autonomy to the patient and responsibility to the patient to tell you if there's a problem you know” P014 [Registrar, upper GI clinic]*

Continuity of care following oncology outpatient consultations

Participants indicated continuity of care for pain management was facilitated by CNS, relationships between oncology HCPs and supportive services (i.e. palliative care teams, pain management services), re-assessment and monitoring of cancer pain between primary and secondary care and self-management plans to manage cancer pain at home.

Utilisation of outpatient oncology CNS

Most registrars and consultants entrusted CNS with following up patients and providing pain management support beyond their initial consultation with an oncologist. This was a component of the CNS role to undertake follow-up remote consultations (i.e. telephone or video call) including the re-assessment of pain and other symptoms:

> *"I have the support of CNSs, it will be within days [referring to follow-up calls], you know hopefully within a week then I have somebody else checking in on them as to whether medication levels need increasing" P007 [Consultant, prostate clinic].*

Consultants reflected on a CNS ability to build rapport with patients and provide a personalised continuity of care making patients more willing to openly disclose their pain. One example showed CNS identifying problematic pain with a patient and escalating this to the consultant to be explored further at follow-up consultations so changes can be made to medication:

> *"If there's a note or a, verbal reminder [referring to a nurse providing notes to a consultant about a patient's pain]. Actually, they have had some problems with*

> *pain or this particular issue then that definitely works well" P011 [Consultant, haematology clinic].*

If there were little or no CNS staff available to support the management of pain following consultations with an oncologist, participants suggested it placed strain on other HCPs to fulfil this role. Consultants and registrars expressed concerns for having *"triple booked clinics"- [P003]* and calling patients *"three hours after their appointment time"-[P003]* when there were no CNS staff to support clinics.

Integration of supportive services

Relationships between supportive services (i.e. palliative care, community nursing teams and pain team) and oncology HCPs were essential to cancer pain management. While HCPs expressed confidence in their ability to identify and treat cancer pain, there were circumstances where HCPs described *"reaching their limits"- [P012]* on providing recommendations on complex opioid medication and required specialist support:

> *"we're used to drugs like Gabapentin, Amitriptyline but when patients are still having pain, that's when you need help and we're lucky, we can ring the palliative care team and there is somebody that can review the patient…usually you can get access to that specialist advice if you need".P012 [Consultant, lung clinic]*

In some cases, the level of responsibility and expertise the clinician felt they had over managing a patient's pain (i.e. pain was important part of consultation discussions) influenced whether a patient would be referred to another team or managed by themselves. Data suggested optimal pain management often involved HCPs identifying and monitoring pain whilst utilising supportive services for advice and guidance to develop appropriate treatment pathways.

Reassessment and monitoring of cancer pain between primary and secondary care

Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make amendments to medication more frequently. In OS a clinicians' opportunity to re-assess and monitor cancer pain was constrained by the frequency of appointments on weekly, monthly or greater basis. Some oncology OS support patients from *"large geographical areas"-[P005]* therefore patients might not return for consistent follow-up appointments. Participants reported this made it difficult for HCPs to provide continuity of care and put more dependency on managing cancer pain between primary and secondary care:

> *"What we don't have a mechanism like we do on the ward…We simply don't have that contact, so we are next seeing the patients usually in three or six weeks' time. So the pattern of medical interaction it simply doesn't map on to pain relief" P018 [Consultant, breast clinic]*

HCPs emphasised pain management decisions needed to be made in line with the patient's needs and their ability to conveniently access primary care. As a result of this, patients and HCPs often had to *"rely on the GPs to issue drugs and escalate pain control"- [P014]*:

> *"We would also encourage patients to seek support from the GP and there will come a time when it's beyond our scope" P005 [CNS, upper GI clinic]*

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

Due to the challenges with assessment and re-assessment in OS, some HCPs suggested providing a "*safety net*"*-[P016]* for the patient was a crucial aspect to ensure cancer pain was adequately reviewed. This involved developing a strategy so a patient knew what to do if the pain relief was not effective or if they were still experiencing severe pain:

> *"I want you to see how those go and then perhaps give them a time period, so this is gonna take a few days for this to start to work better. If things are not any better, then to call us back" P016 [Consultant, haematology clinic]*

Some HCPs provided patients with documentation that included information on how, when and what medication to take, as well as contact information for the OS and out-of-hours services. This was one-way HCPs ensured patients were supported to self-manage cancer pain at home:

"If there is anything of concern there is a number that you can call 24 hours a day, 7 days a week, 365 days a year and then we can see them on the acute unit and take it from there" P006 [Registrar, urology clinic]

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 (6, 8). 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 (19). Pain management tools can be efficient especially when HCPs have limited time or when pain assessments are combined with an individualised assessment to fully understand how pain is affecting the patient physically, psychologically, socially and culturally.

Our data show that pain management in oncology outpatient services was influenced by variation in HCPs' expectation of responsibility for pain management; i.e. it was often considered to be someone else or another services' responsibility. This diffusion of responsibility is well reported in healthcare settings and is known to lead to underperformance of clinical activities and fragmented care in circumstances of shared accountability (20) Fallon et al. (2018) showed that when structured pain assessment processes are implemented within routine clinical care, this leads to a more consistent approach to pain management, a reduction in the diffusion of responsibility and improved pain outcomes for cancer patients (11).

Our data showed 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 (21). However, our data shows that HCPs who expressed clinical responsibility around pain management were inclined to develop self-management plans to support patients to manage cancer pain at home.

This study aimed to describe current pain management and thus the interview topic guide was not developed to explored nuances of self-management practices. However, we know from previous studies there is variation in self-management approaches (22). In OS, development of self-management support for patients is crucial to a continuity of care. This includes providing elements of educational interventions to facilitate problem solving and adequate decision-making skills and tailoring recommendations to the individual's situation and defining goals with action plans (22). By developing supportive plans, it ensures patients understand what to do if pain escalates or becomes unmanageable. Subsequently, it could encourage patients to initiate re-assessment of their pain at primary and secondary care services.

We found system-level challenges impacted the extent to which pain was explored with patients and monitored by outpatient HCPs. Exacerbated by the impact of the COVID-19 pandemic, clinics are often over-booked, short staffed, and have long waiting lists (15). In addition, our data show that the complexity surrounding the interface between primary and secondary care and challenges with integration of multi-disciplinary teams meant continuity of care, in particular re-assessment and monitoring of pain, was difficult as patients were referred back to primary or community care teams.

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

Oncology literature has highlighted the benefits for the use of remote consultations in cancer pain management, where it is used appropriately. For example, reduction in pain severity scores, cost-effective, improved accessibility for patients to receive HCP advice and treatment of symptoms and aided monitoring and re-assessment of symptoms (23, 24). We found adaptations to pain assessments for remote care impeded experienced HCPs to do a detailed thorough pain assessment, especially if not Audio Visual (AV) facilitated. HCPs become experts in their field through knowledge, skill, training and experiential learning (25). Since COVID-19 the increased use of remote consultations has meant HCPs have to spend more time doing pain assessments remotely. However, due to a lack of experiential learning for conducting pain assessments through remote consultations, this potentially made even experienced HCPs feel like a novice. This coincides with the novice to expert theory (25). Similarly, for those with less experience a change in mode-of-consulting could further impede thorough pain assessments for patients. Without additional support and structured guidance on how to conduct remote consultations there is a risk that patients' pain will not be appropriately managed and key components of a detailed pain assessment potentially missed. Previous research has shown even when pain assessments are standardised and detailed, only modest improvements in pain for patients with cancer are observed, largely because of low delivery fidelity and poor implementation (6). However, Fallon et al. (2018) demonstrated that when standardised pain assessment processes are integrated within routine clinical practice at the level of the service (rather than at an individual clinician level) this leads to greater improvements in pain outcomes for patients and more appropriate analgesic prescribing. This suggests an in-depth implementation plan at service-level would be crucial to the success of a structured pain management intervention.

Strengths and limitations

A structured sampling framework was developed by the research team which may have resulted in potential bias. However, this approach provided a heterogeneous sample of staff roles, seniority and clinical speciality that gave a greater understanding to the management of different types of pain prevalence patients experienced. All participants were from Northern England; therefore, the study's findings may not be generalisable to other regional oncology outpatient settings or international healthcare systems. One limitation is related to our recruitment strategy (i.e. self-referral sampling after HCPs received an information pack); due to the nature of the research aims (i.e. pain management in oncology) participants with strong negative or positive views may have been more likely to agree to participate. However, the themes identified from the data indicated broad perspectives of pain management processes and experience, so it is unlikely that we have sampled an exclusively polarised group of participants.

Implications of clinical research and practice

Faculty of Pain Medicine Core standards for cancer pain management (12) state all patients should receive a pain assessment at each encounter with an oncology clinician that includes exploration of intensity, mechanisms, aetiology and impact. Evidence from clinical trials show that standardising pain assessment in oncology outpatient clinics leads to improvements in patients' pain and quality of life (11). This research recommends the implementation of a structured routine pain assessment that minimises the risk of diffusion of responsibility and encourages HCPs to incorporate the most crucial components of a pain assessment into patient consultations (i.e. exploration of intensity, mechanisms, aetiology and impact). Secondly, at a service level, uncontrolled cancer pain remains the most common reason for contacting GP out-of-hours service (10). Implementing a structured pain assessment within oncology OS would encourage patients to report pain earlier, enabling HCPs to manage cancer pain earlier, reducing the burden on GP out-of-hours service, and minimising the risk of patients living with undertreated cancer pain.

Conclusion

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

List of abbreviations

HCP – Healthcare Professionals

OS – Outpatient Services

CNS – Clinical Nurse Specialist

Upper GI - Upper Gastrointestinal tract

NHS – National Health Service

AV – Audio Visual

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 interest's statement

None declared.

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Authors' contribution

MM is the chief investigator for this study; he conceived the project, led the design and writing of the study protocol, facilitated data analysis and drafting of this manuscript. Methodology (OR, MM). Project administration (OR, MM).

OR wrote the study protocol, including drafting the topic guide, completed data curation, data collection and transcribed interviews. OR led the data analysis and interpretation of the data. Review of interpretation of the data and analysis was done by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. Writing-review and editing (OR, MM, SR). All authors (OR, SP, KF, NC, MF, SR, CM, EB, DS, AH, SH, MM) contributed to manuscript revision, read and approved the submitted and revised version.

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Yorkshire Cancer Research

UNIVERSITY OF LEEDS

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.

Interview topic guide Version 0.1 06.10.2021 IRAS: 305397

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

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

❖ *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	☒	1
2.	Abstract	☒	2
3	Problem formulation	☒	3
4.	Purpose or research question	☒	4
5.	Qualitative approach	☒	4
6.	Research characteristics and reflexivity	☒	5
7.	Context	☒	4
8.	Sampling strategy	☒	4
9.	Ethical Issues	☒	5/18
10.	Data collection methods	☒	5
11.	Data collection instruments and technologies	☒	5
12.	Units of study	☒	6
13.	Data processing	☒	5
14.	Data analysis	☒	6/7
15.	Techniques to enhance trustworthiness	☒	5
16.	Synthesis and interpretation	☒	5
17.	Links to empirical data	☒	8-13
18.	Integration with prior work, implications, and contribution to field	☒	14-16
19.	Limitations	☒	16
20.	Conflict of interest	☒	18
21.	Funding	☒	18