



UNIVERSITY OF LEEDS

This is a repository copy of *Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study*.

White Rose Research Online URL for this paper:  
<http://eprints.whiterose.ac.uk/94298/>

Version: Accepted Version

---

**Article:**

Hackett, J, Godfrey, M and Bennett, MI [orcid.org/0000-0002-8369-8349](https://orcid.org/0000-0002-8369-8349) (2016) Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study. *Palliative Medicine*, 30 (8). pp. 711-719. ISSN 0269-2163

<https://doi.org/10.1177/0269216316628407>

---

© The Author(s) 2016. This is an author produced version of a paper accepted for publication in *Palliative Medicine*. Uploaded in accordance with the publisher's self-archiving policy.

**Reuse**

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.



[eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk)  
<https://eprints.whiterose.ac.uk/>

# **Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study**

Julia Hackett,

University of Leeds, Academic Unit of Palliative Care

Mary Godfrey,

University of Leeds, Academic Unit of Elderly Care and Rehabilitation

Michael Bennett, University of Leeds, Academic Unit of Palliative Care

Email addresses:

Hackett J: [j.e.hackett@leeds.ac.uk](mailto:j.e.hackett@leeds.ac.uk)

Godfrey M: [m.godfrey@leeds.ac.uk](mailto:m.godfrey@leeds.ac.uk)

Bennett M: [m.i.bennett@leeds.ac.uk](mailto:m.i.bennett@leeds.ac.uk)

Contact for Correspondence:

Mary Godfrey

Reader in Health and Social Care  
Leeds Institute of Health Sciences  
Academic Unit of Elderly Care and Rehabilitation  
Room 2.12  
Charles Thackrah Building  
101 Clarendon Rd.,  
Leeds LS2 9LJ  
Tel. +44 113 343 3959

## **Abstract**

**Background:** Despite advances in treatment of pain in advanced cancer, it remains a major source of suffering with adverse effects on patients' life quality. There is increasing understanding of its multi-dimensional nature and the variable responsiveness of medication to complex pain. Less clear is how patients and their caregivers respond to, and manage pain complexity.

**Aim:** To explore patients' and carers' experiences of advanced cancer pain and the processes that they engage in to manage pain.

**Design:** Qualitative study employing face-to-face interviews at two time points and audio-diaries. Data were analysed using grounded theory strategies.

**Setting/participants:** Purposive sample of 21 advanced cancer patients and 16 carers from oncology outpatients in a tertiary cancer centre and a hospice.

**Results:** Three distinct patterns of pain were discerned in patients' accounts, distinguishable in terms of complexity, severity, transiency, and degree of perceived control over pain. Pain was dynamic reflecting changes in the disease process, access to, and effectiveness of pain relief. For patients' and carers', neither pain relief nor expertise in pain management is secured once and for all. The main drivers of help-seeking and action by patients to manage pain were: the sensory experiences of pain and meaning attached to it; not beliefs about analgesia.

**Conclusions:** The complex and dynamic nature of pain and how it was understood shaped help-seeking and pain management. Variable effectiveness of pain relief for different pain types were challenging for patients and professionals in achieving relief.

## **Keywords**

Palliative Care, Advanced Cancer, Analgesia, Pain, Qualitative Research

## **What is already known about the topic?**

- Advanced cancer pain is still reported as common, severe, and undertreated
- Patients' attitudes and beliefs impinge on use of medications, particularly morphine, to manage pain

## **What this paper adds?**

- The dynamic, complex and multi-dimensional nature of pain presents a major challenge for patients and professionals to manage it and to secure good enough relief
- Although attitudes and beliefs towards analgesics vary, they do not drive patient behaviour. Rather, patients' sensory experiences of pain, particularly severity, and its meaning, shaped behaviour with consequences for how pain was managed
- The multidimensional nature of pain meant that many patients were taking a wide range of pain medications i.e.: non-opioid analgesics, compound analgesics, slow release opioids, and anticonvulsants. The acceptability of rescue morphine varied depending on patients' sensory experiences of pain

## **Implications for practice, theory or policy**

- Pain management in advanced cancer is more accurately conceived of as a trial and error process for patients and professionals

- Clinicians should be aware of the use of rescue morphine in patients who are opioid naïve
- There is need for longitudinal studies to examine transitions between pain states in advanced cancer, how they are responded to by professionals and managed by patients

## Introduction

Pain continues to be a major source of suffering in advanced cancer with adverse effects on patients' life quality<sup>1-3</sup> and caregiver distress<sup>4-6</sup>. A meta-analysis of pain prevalence<sup>7</sup> found a rate of 64% among advanced cancer patients, of whom more than one third graded their pain as moderate or severe. There is increasing recognition of the complexity and multi-dimensionality of pain, varying in type, source, intensity, duration and site, experienced singularly or in combination, and is imbued with meaning<sup>8</sup>. This includes different types of pain such as neuropathic<sup>9</sup>, incident or breakthrough<sup>2</sup>, and bone pain<sup>10</sup> associated with poor pain control and with negative impact on physical, cognitive and social functioning and mood. Further, since these types of pain are both disease and treatment related, expansion of new treatment modalities that extend life, thus lengthening the advanced trajectory stage, mean that prevalence of complex pain is likely to increase<sup>11</sup>. The meaning and consequences of the multi-dimensional nature of pain in advanced cancer and the differential responsiveness of varying types of pain to opioid analgesia<sup>9,12</sup> has not thus far informed understanding of how patients manage their pain. Further, the lengthening of the advanced cancer trajectory and increased risk of complex pain creates new challenges for patients in managing it. However, from the perspective of patients, the literature typically construes cancer pain as singular, linear, cumulative in nature, and inevitable as death approaches<sup>13</sup>. At the same time, research interest has primarily focused on under-treatment of cancer pain, and particularly on the attitudes and beliefs of patients that impinge negatively on medication adherence generally and on morphine specifically<sup>13-15</sup>. Reported in systematic reviews<sup>16, 17</sup> and qualitative synthesis<sup>18</sup>, these include: fear of addiction and side effects, the desire to be seen as a "good patient", beliefs that pain

signifies progression of the cancer and that pain is inevitable. The underpinning theory is that attitudes and beliefs inform behaviour and lead to poor adherence to medication regimens that in turn give rise to sub-optimal pain relief. While this theory has informed research on educational interventions to tackle sub-optimal pain management practices, a recent review of reviews concluded that although such interventions can have a very small impact on pain intensity, their clinical significance is questionable<sup>19</sup>.

There appears to be a knowledge gap between the conception of pain in the medical literature as complex and heterogeneous and the processes whereby patients with advanced cancer experience, understand and manage pain in everyday life.

## **Aim**

The aim of this study was to examine how patients with advanced cancer and their caregivers experienced pain complexity, the meaning they attached to it, how they managed it and what shaped their perspectives and actions. It thus provides insight into an important theoretical and practical gap in current understanding of cancer pain.

## **Methods**

We employed a qualitative interpretive approach. The study was conducted in two service settings in a Northern English city: oncology outpatients' clinics within a tertiary cancer centre, and a hospice palliative care service, to include patients at different stages in the disease course. It was part of a research programme on the management of advanced cancer pain. Research ethics committee approval was obtained (National Research Ethics Service (NRES) Committee South West – Cornwall & Plymouth; 12/SW/0287).

## **Participants**

Inclusion criteria were: experiencing pain, living at home, over the age of 25, with advanced cancer (defined as active and non-curative). Purposive sampling was used to identify patients at different points in the disease course with different types of cancer. Our assumption was that recruiting patients from oncology and palliative care would ensure inclusion of individuals at different points in the disease course. Patients were initially approached by oncologists and research nurses from out-patient clinics in eight speciality cancer areas (lung, breast, colorectal, head and neck, prostate, gynaecological, upper GI, and renal); and by clinical nurse specialists for those receiving palliative care services. Following expressions of interest, the first author (JH) discussed participation with interested individuals in person or by telephone and obtained informed consent.

## **Data collection**

In-depth, face-to-face interviews were carried out at two time points, six weeks apart to capture change over time. These were a combination of dyadic (patients and their caregiver together) and individual interviews, conducted primarily by JH, mainly in patients' homes. Dyadic interviews sought to explore the collective, inter-dependent perspective of patient and caregiver in pain understanding and management<sup>20,21</sup>.

Interviews were guided conversations to elicit accounts of participants' experience in their own words at a pace determined by them, using a topic guide (Appendix 1). This was used flexibly as an aide memoire to discuss experience of illness and pain. Second interviews incorporated specific prompts to pursue analytic ideas, for example, transitions in the pain experience and how these were managed. A sub-sample of patients was selected based on



their varied experiences of pain and asked to complete audio diary in-between interviews, to obtain a contemporaneous picture of pain and the response to it.

### **Data analysis**

Interviews and audio diaries were transcribed, and participants chose a pseudonym. Data were collected from April 2013 - January 2014.

We adopted a grounded theory analytic approach<sup>22, 23</sup>. This combined concurrent data collection and analysis with modification to the topic guide to pursue emerging lines of inquiry. Debrief meetings involving the first two authors (JH &MG) took place and were recorded after each interview. They provided space to reflect on the interview process, emotional content, and effect on the researcher, and to explore initial ideas about the data. Further phases carried out by JH & MG separately and together, were familiarisation through multiple readings of transcripts; then open and focused coding and memo-writing to facilitate the development of categories and concepts. Method of constant comparison was used throughout whereby data segments and the developing codes and categories were compared both within cases to identify the temporal sequencing of events, and how these were understood and acted upon, and across cases to examine variation between participants. For example, having developed the analytic categories of pain type and their properties (complexity, intensity and controllability), we examined their consequences in terms of subjective meaning and the work of pain management for patients and caregivers. Throughout, data collection and analysis, data, codes and concepts were discussed within the research team (of varied disciplinary backgrounds: psychology, sociology and academic palliative care medicine); and with the wider steering group, including patient representatives, clinicians and academics. NVivo10 was used to support the analysis.

## **Results**

Twenty-four patients and 18 carers were recruited. Of these, 16 patient/carer dyads and five patients alone completed a first interview; three patients withdrew on account of deteriorating illness. Eleven patient/carer dyads and three patients alone completed the second interview; three had died and four were too unwell to participate. We did not seek to interview caregivers following the death of their relative. Three patients completed the audio diary. 35 interviews were conducted, (27 patient/caregiver dyads). Average interview length was around an hour (range 45-130 minutes). Table 1 provides a profile of patients. All were White British.

Insert table 1 here

### **Stage in advanced cancer**

Although everyone had advanced cancer, the point of diagnosis and stage in the disease process varied. Many were diagnosed with advanced cancer at, or within a short period of their first contact with cancer services. The length of time that people had lived with advanced cancer differed across cancer types. At one end of the spectrum were 5 patients who were diagnosed between 2 weeks and 9 months prior to interview (renal, bowel, ovarian and lung cancer); at the other were those who had lived with advanced cancer for between 4 and 11 years (four patients all with prostate cancer); the remainder were in-between (breast, head and neck, upper GI).

In characterising types and severity of pain, we have used participants' own accounts. Typically, patients employed visceral language and metaphors to differentiate pain texture and intensity.

### **1: Complex: multiple, severe and uncontrolled (8 patients)**

Here, the multiple sources and types of pain, occurring simultaneously and cumulatively, informed the complexity of the pain experience. Whereas morphine reduced some pain to what was described as a constant 'dull ache', other types of pain - persistent and intermittent - overlaid this with the distinctive features of neuropathic, inflammatory and bony pain as described in the medical literature.

In my hips it's a funny pain, it's more of an ache not a pain, like a dull ache, it's as best I can describe it. This [points to shoulder blade] when I get it is like somebody sticking a knife in you...Most strangest thing that puzzles me is my feet, my toes, numb all the time, these 3, little toe next to it. It's a weird feeling, I get completely numb, I can touch it and you can't feel it, it's just completely dead, and then within 2 minutes its right, it's annoying it's not painful.

Graham, P21

For other patients, this type of 'nerve' pain was described as excruciating:

I feel like I had to bite on something to stop me screaming. It was ...like being stabbed, as if I was being chopped up, like a red hot knife or poker in my legs and knees...I was told it's because the tumour's pressing on a nerve...my left leg when I touch it feels numb, like it belongs to someone else.

Betty, P6

Where cancer had metastasised to the bone, common in patients with breast and prostate cancer, 'bony' pain overlaid a constant 'dull ache' with an intensity that was uncontrolled by strong opioids. At the first interview Jenny described new multiple pain sites:

I've lived with this pain in my side now for like 3 weeks and this in my shoulder for nearly 4 weeks. And it's so bad ...my skin just feels like somebody's chucked hot water at it, it's, it's just like with radiotherapy, just like burning... they say to me at the hospital it's probably the cancer ...that's gone into that particular bone....

Jenny, P3

In her audio diary, she recounted how the x-ray revealed several rib fractures, resulting in pain severity, "like a 10 plus" with the consequence that she didn't want to do anything or go anywhere, couldn't sleep or lie down, and cried 'bucket loads' - from pain and associated low mood. Whereas, her regular slow release opioids kept background pain to an ache, the increased dosage of rescue morphine didn't touch this pain. Offered radiotherapy to relieve it, Jenny reported in the second interview that the intensity had reduced somewhat. She anticipated that similar type pain would emerge elsewhere.

Aspects of this pain experience was perceived as 'uncontrollable' in persistence and severity, albeit all in this group when interviewed were using a combination of non-opioid analgesics, compound analgesics, slow release opioids, rescue morphine, and anticonvulsants.

## **2: Complex: multiple, intermittently severe, partially controlled (8 patients)**

The predominant feature of pain here was intermittent, oscillating pain, occurring at unpredictable intervals, over a day or days, without identifiable triggers. A typical form of this type of incident pain is illustrated below:

My pain I would say is moderate now...then I get these awful headaches...feels my head is going to explode...and I take the Oromorph then...which helps...I have to have a bottle of that always, otherwise I panic.

Angus, P2

Less typical was the form described by Ruth:

The pain in the middle of the stomach...It can come and go just as easy, and I've had it last all day and all night...like a griping spasm...It comes to a climax for a second ...climaxes like a gripey pain and then it subsides and it makes all these squidgy noises ...that varies as to how strong it is...can be excruciating...you don't know where to put yourself..., then 3 minutes later it's doing it again and that can go on anything up to 12 hours and then it just will go and I don't know why, can't follow a pattern at all.

Ruth, P24

Sometimes, but not always, this type of incident pain was relieved with rescue morphine. Lack of consistent experiential evidence that 'rescue morphine' worked, resulted to patients and carers questioning its continued use for such pain.

Typically, patients with this type of pain pattern were prescribed a combination of non-opioid analgesia, slow release and rescue morphine, although actual use of the latter was inconsistent.

### **3: Multiple, simultaneous, low severity, 'controlled' (5 Patients)**

Here, pain intensity was overall low, but punctuated by occasional more intense pain. Such a pattern was reported by patients in the early advanced cancer stage:

There's 2 types really...sometimes I get a really sharp pain and the other sort of pain is like a... well it's more ache, a bit like a period pain actually...I feel it in my hips...like pushing down when you're pregnant.

Nicole, P 14

Although Nicole was prescribed Paracetamols and codeine, both were only used when needed, "sometimes Paracetamols' enough, but if it isn't I take a codeine".

This pain pattern was also present for patients who were near the end of life when pain was not a major feature of the cancer. Whereas such patients might have experienced considerable pain leading up to diagnosis and subsequently, fatigue and weakness, leading to inactivity, meant that pain was not viewed as a problem now, although other symptoms like sickness, diarrhoea or constipation were strongly manifest. Thus George, whose second interview was around 5 weeks before his death, only got up for a couple of hours during the day.

I can put myself completely out of pain by going and laying down.

George, P9

At the time of interview analgesics for this group ranged from Paracetamols to weak opioids, and rescue morphine. Several had been prescribed opioids during treatment or post surgery, but had stopped as they considered they had no need of them. From second interviews, it appeared that for some patients here, awareness of subtle shifts in the intensity of intermittent pain were opening up the possibility that medication dose and type might need to be reviewed.

### **The meanings of pain and help seeking behaviours**

Patients discussed pain in terms of its physical, emotional, and existential dimensions, and its impact on what they could do. Accounts of severe, persistent pain adversely affected mood; and inability to secure relief exacerbated sense of loss of control. Pain that was unpredictable had similar emotional impact. Complex pain in its different forms was disruptive of routines that had already narrowed as a result of the cancer. Escalating pain as well as change in type and/or source was perceived as indicative of disease progression; signifying that life was time limited. The reality was that a new onset of pain at a different site or an increase in severity was often sign of metastatic spread. Consequently pain was embodied within conflicting emotions and uncertainties. For some patients, this was a potential barrier to seeking support<sup>24</sup>.

Sometimes I leave the suffering to the end because I think if I go in with suffering they're going to find something else. Like my chest infection, I think I've got lung cancer when I haven't. Everything I think is connected to my cancer, so when I get pain in an area I think this is it.

Jason, P1

However, although Jason delayed talking about his pain with the oncologist until the point that he could only walk with difficulty, this precipitated a referral to the hospice for support with pain management.

But focus on pain and the possibility and hope of finding a new means of relieving it, could also be a distraction from thoughts of death. At several points during the interview, Max's wife, Eliza, asserted that they were concentrating on getting better pain relief; it was the pain and not the cancer that was 'wiping him out'. When Eliza went out of the room for a moment, he remarked:

I'll be honest ...I've not told Eliza...she'd get carried away. Since I started on this cancer drug, I'm pretty sure in myself that my back pain has reduced.

Max, P7

At the same time, the association of palliative care with closeness to death was also a barrier for some patients in receiving supportive care for pain.

### **Processes of pain management**

While multiple types of medication delivered in different forms (fentanyl patches, capsule and oral) were the mainstay of pain management for patients experiencing complex, persistent, severe pain, pain wasn't managed in the sense of being controlled. Whereas medication might reduce background pain to a 'dull ache', other types of pain were perceived as unrelieved. Unrelieved pain included stabbing pain at unpredictable intervals that could last for extended periods of time; crippling pain running up and down the legs that eased only when sat or lay down; and pins and needles and numbness. Paradoxically, the gap between the multiple types of pain medication and the lack of relief placed a question mark over whether it was worth taking it.



So if I did stop taking them, what would I be like? ...Ridiculous that, I could be twice as bad...But obviously I take them because it's erm, well I've been told to take them by the hospital and the doctors so err I do, I do take them as and when I should do.

Bailey, P18

Patients additionally employed diverse non-pharmacological strategies to secure relief. Betty massaged her legs which eased the pain a little; Dan tried spearmint drinks; Betty and Jenny accessed Reiki at the hospice which although it didn't reduce the pain helped them to feel better in themselves.

Patients also described a sense of helplessness at their inability to relieve the pain. Being unable to do 'normal' things like get outside to the shops; potter in the garden; being with others, affected well-being. The process whereby pain affected mood was spiral: sensory experience contributed to low mood and inability to do things they enjoyed, and exacerbated helplessness and despair. Caregivers also felt helpless and uncertain in face of unrelieved pain. Dan's wife was torn between wanting to help and unsure as to whether she was doing the right thing:

We do ... hot water bottles, in the middle of the night when he wakes in pain and give him a tablet, so... I mean it's hard because you're frightened that you might just give him too many... you see he'd take one, and pain doesn't go, so I was worried of giving another one and I'd say, "But you can't have another one." It's like Paracetamols, he'd take them and say, "Well can I have some more?" and I'm saying, "No, you can't take any more yet," and of course he wor getting upset 'cos he's saying that I wasn't giving him his medication, You're holding it back and I'd say: "No,

I'm not." So ...Yeah, 'cos I mean you don't like to see anybody in pain, but I just kept thinking you can't give him too much, else it might over... I mean I don't know whether it would have overdosed him or not, but it was...But it was difficult dealing with it, knowing how much to give him.

Hannah, C17

For patients with intermittently moderate to severe, partially controlled pain, non-opioid analgesia and strong opioids were key resources in managing it. Patients also used morphine to manage the rhythm of their day, to maximise what was most important to them.

I know how much morphine to take now and to sleep..., my sleep comes first... it might seem a waste to spend so much time asleep, but without that sleep then there's no life at all...I come here [day hospice] on a morning and then I have a sleep on an afternoon and that way I can have a nice evening with my wife and with my children.

Angus, P2

For patients with this pain pattern, rescue morphine was often the first opioid prescribed. Although advised to use it 'as and when needed', dosage and frequency were a source of uncertainty. Dick described 'swigging the bottle' during the night when pain severity stopped him sleeping:

I'd no pain for 24 hours...but was sick every half hour for five hours after waking...it was too easy to take.

Dick, P8

He subsequently negotiated with his doctor to go on regular morphine instead.

Side effects of rescue morphine, in context of intermittent pain, had the consequence that use was limited or stopped.

I did take it [Oromorph] sometimes on a night when I was going to bed, but I thought is it worth it? Because it gives me terrible nightmares, I didn't like the nightmares. So I thought well if I can stop taking that and it cures the nightmares, I would rather have the pain.

Harry, P10

Similarly, feeling sleepy and dulled foggy thinking restricted use of rescue morphine in conditions where slow release opioids were perceived as necessary to manage the pain.

Although our sample represented a range of different types of cancer and trajectories, our data showed that it was the severity of pain that was the distinguishing characteristic which posed implications and consequences for the processes which patients and their families engaged in to manage it.

## **Discussion**

Advanced cancer patients' lives are shaped by their illness, demands of treatment, and intrusive symptoms that affect what they can do, of which pain is among the most prevalent<sup>7</sup>. Pain is complex, multidimensional and dynamic<sup>8-11</sup>. How this is experienced and understood by patients and informs pain management practices including use of medication, was focus of this study. We highlight three broad patterns of advanced cancer

pain that illustrate the variability of pain at this stage. These demonstrate the dynamic, complex, and non-linear nature of pain, and show how patients' sensory experiences shape the meaning of pain, the strategies employed to manage it and their perception of the possibility of achieving control over pain with implications for life quality. For those with severe pain, it was evident that the pain experience was not simply the consequence of 'non-adherence' to prescribed medication; it also reflected the uneven responsiveness of pain complexity to medication, including strong opioids.

Pain complexity aligned with disease progression and the impact of treatments to extend life mean that the pain experience is not static but dynamic; developing expertise in its management is not a once off achievement for patients. Moreover, evaluating and responding optimally to pain complexity also involves professionals in 'trial and error' regarding particular combinations of pharmacological and other therapeutic options.

It was notable that even within a relatively short period of six weeks, changes occurred in patients' experience of pain. However, the existential meaning attached to cancer and cancer pain, particularly the fear that pain signals disease progression could operate to delay patients' communication to professionals about it. Similarly, patients association of palliative care with end of life could affect use of specialist pain management support.

Whilst our data showed the presence of a range of beliefs that are reported in the literature as barriers to morphine<sup>16, 25-30</sup>, they were not central in driving behaviour. Within our sample the majority of patients reported taking non-opioid analgesics, compound analgesics, strong opioids and slow release opioids. However, the use of rescue morphine varied depending on patients' sensory experiences of pain. There were two sets of circumstances in which intake of rescue morphine, although prescribed, was limited. One

related to those patients who experienced moderate to severe incident pain which they considered rescue morphine was not touching. The other was where patients either considered their level of pain could be managed without the use of rescue morphine; or introduced to opioids for the first time through this mode of delivery resulted in physical and cognitive effects regarded as intolerable. For opioid naive patients<sup>31</sup> particularly, their experiences of adverse effects resulted in limited use or ended use, at least at this stage in their pain. For those who were opioid tolerant but limited their intake of rescue morphine, we posit that this was as a result of the permissiveness of rescue morphine and that there was a lack of equilibrium in the trade-off between their perceived need for relief and side effects<sup>11</sup>.

## **Limitations**

Our study was conducted in one country and our sample consisted of one ethnic group, therefore it may reflect a specific cultural perspective. However, being located in a tertiary cancer centre with systems in place to effect transition to supportive care for symptom relief alongside non-curative treatment, means that patients accessed multiple types and combinations of pharmacological pain relief, as well as radiotherapy. There was considerable overlap between patients recruited from oncology outpatients and palliative care in their advanced cancer stage. This means our characterisation of pain complexity may not exhaust the types of pain experience in advanced cancer, particularly the process of transition and decision-making between pain states. Despite these limitations, this study has important strengths. Patients in our sample represented a range of different cancer types, ages, and both genders. They had varying levels of pain severity; experienced different types and combinations of pain, from both singular and multiple sites; and used

analgesics ranging from occasional paracetamol to a combination of strong opioids. The use of in-depth longitudinal interviews and audio diaries provided us with a richer understanding of the dynamic changes in pain over the illness trajectory<sup>32</sup>.

## **Conclusion**

Advanced cancer pain is dynamic and complex. Patients (and caregivers) assume an active, agentic role in managing pain. Beliefs about analgesics did not drive patient behaviour. Instead, patients' sensory experiences of pain, particularly of severity, and what they perceived pain to mean, drove help seeking and action to manage pain. There are challenges in securing pain relief in relation to different types of pain and their differential responsiveness to medications.

There is a need for more longitudinal research to examine transitions between pain states in advanced cancer, how these are responded to by services and managed by patients, thus taking understanding of pain beyond pre-occupation with pain barriers.

## **Author's contributions**

M.B. and M.G. proposed the idea for the study and MG developed the design. J.H. and M.G. carried out the data collection, and conducted data analysis. J.H. wrote the first draft of the manuscript and all authors contributed to the writing of the final version.

## **Acknowledgements**

We would like to thank all the patients and carers for taking their time to take part in our study and for sharing their views and experiences. We would also like to thank the health professionals who helped us to identify and contact participants.

## Declaration of conflicting interests

The authors declare that there is no conflict of interest.

## Funding

This paper summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (“Improving the Management of Pain from Advanced Cancer in the Community (IMPACCT)” RP-PG-0610-10114). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

## References

1. Ferrell BR. The impact of pain on quality of life: a decade of research. *The Nursing Clinics of North America*. 1995; 30: 609-24.
2. Portenoy R and Lesage P. Management of cancer pain. *The Lancet*. 1999; 353: 1695-700.
3. Grant M, Rhiner M and Padilla G. Home care: maintaining quality of life for patient and family. *Oncology*. 1992; 6: 1421-8.
4. Yates PM, Aranda S and Edwards EA. Family caregivers experiences and involvement with cancer pain management. *Journal of Palliative Care*. 2004; 20: 287-96.
5. Wittenberg-Lyles E, Demiris G, Parker CR, Oliver D and Burt S. Reciprocal suffering: caregiver concerns during hospice care. *Journal of Pain and Symptom Management*. 2011; 41: 383-93.
6. Ferrell B, Grant M, Borneman T, Juarez G and ter Veer A. Family caregiving in cancer care management. *Journal of Palliative Medicine*. 1999; 2: 185-95.
7. van den Beuken-van Everdingen M, de Rijke J, Kessels A, Schouten H, Kleef van M and Patijn M. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Annals of Oncology*. 2007; 18: 1437-9.
8. Davis M and Walsh D. Epidemiology of cancer pain and factors influencing poor pain control. *American Journal of Hospice and Palliative Medicine*. 2004; 21: 137-42.
9. Rayment C, Hjermstad M, Aass N, et al. Neuropathic cancer pain: Prevalence, severity, analgesics and impact from the European Palliative Care Research Collaborative - Computerised Symptom Assessment Study. *Palliative Medicine*. 2013; 27: 714-21.
10. Falk S and Dickenson AH. Pain and nociception: mechanisms of cancer-induced bone pain. *Journal of Clinical Oncology*. 2014; 32: 1647-54.
11. Portenoy RK. Treatment of cancer pain. *The Lancet*. 2011; 377: 2236-47.

12. Green CR, Montague L. and Hart-Johnson TA. Consistent and breakthrough pain in diverse advanced cancer patients: a longitudinal examination. *Journal of Pain and Symptom Management* 2009; 37: 831-847
13. Reid C, Gooberman-Hill R and Hanks GW. Opioid analgesics for cancer pain: symptom control for the living or comfort for the dying? A qualitative study to investigate the factors influencing the decision to accept morphine for pain caused by cancer. *Annals of Oncology*. 2008; 19: 44-8.
14. Coyle N. In their own words: seven advanced cancer patients describe their experience with pain and the use of opioids. *Journal of Pain and Symptom Management*. 2004; 27: 300-9.
15. Paice J, Toy C and Shott S. Barriers to cancer pain relief: fear of tolerance and addiction. *Journal of Pain and Symptom Management*. 1998; 16: 1-9.
16. Jacobsen R, Moldrup C, Christrup C and Sjogren P. Patient-related barriers to cancer pain management: a systematic exploratory review. *Scand J Caring Sci*. 2009; 23: 190-208.
17. Deandrea S, Montanari M, Moja L and al e. Prevalence of undertreatment in cancer pain: A review of the published literature. *Annals of Oncology*. 2008; 19: 1985-91.
18. Flemming K. The use of morphine to treat cancer-related pain: a synthesis of quantitative and qualitative research. *Journal of Pain and Symptom Management*. 2010; 39: 139-54.
19. Adam R, Bond C and Murchie P. 'Educational interventions for cancer pain: A systematic review of systematic reviews with nested narrative review of randomized controlled trials'. *Patient Education and Counseling*. 2015; 98: 269-82.
20. Morris SM. Joint and individual interviewing in the context of cancer. *Qualitative Health Research*. 2001; 11: 553-567.
21. Polak L and Green J. Using joint interviews to add analytic value. *Qualitative Health Research*. 2015; DOI: 10.1177/1049732315580103
22. Charmaz K. *Constructing Grounded Theory 2nd Edition*. London: SAGE pUblications Ltd, 2014.
23. Corbin M, J and Strauss A. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 3rd ed. London: SAGE, 2008.
24. Kwon J. Overcoming barriers in cancer pain management. *Journal of Clinical Oncology*. 2014; 32: 1727-2117.
25. Edrington J, Sun A, Wong C, et al. Barriers to pain management in a community sample of chinese american patients with cancer. *Journal of Pain and Symptom Management*. 2008.
26. Pargeon K and Hailey B. Barriers to effective cancer pain management: a review of the literature. *Journal of Pain and Symptom Management*. 1999; 18: 358-68.
27. Ersek M, Miller Kraybill B and Du Pen A. Factors hindering patients' use of medications for cancer pain. *Cancer Practice*. 1999; 7: 226-32.
28. Ward S, Berry P and Misiewicz H. Concerns about analgesics among patients and family caregivers in a hospice setting. *Research in Nursing and Health*. 1996; 19: 205-11.
29. Ward S, Carlson-Dakes K, Hughes S, Kwekkeboom K and Donovan H. The impact on quality of life of patient-related barriers to pain management. *Research in Nursing and Health*. 1998; 21: 405-13.
30. Ward S and Gatwood J. Concerns about reporting pain and using analgesics: a comparison of persons with and without cancer. *Cancer Nursing*. 1994; 17: 200-6.



31. Mercandante S, Porzio G, Ferrera P, et al. Low morphine doses in opioid-naive cancer patients with pain. *Journal of Pain and Symptom Management*. 2006; 31: 242-7.
32. Kendall M, Murray S, Carduff E, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*. 2010; 340 (7739): 196-9.

**Table 1: Patient characteristics**

Pseudonym	Age	Gender	Recruited from:	Primary Tumour Site	Diagnosed	Diagnosis with advanced disease	Living situation	Pain Pattern
Jason	46	M	Palliative Care	Prostate & bone mets	2009		With spouse/partner	2
Angus	49	M	Palliative Care	Brain tumour	2011		With spouse/partner	2
Jenny	55	F	Palliative Care	Breast & bone mets	1997	2011	With spouse/partner	1
Eunice	73	F	Palliative Care	Breast; lung & brain mets	2010	2011	Alone	2
Betty	80	F	Palliative Care	Bowel; bone & pelvis mets	2013		Alone	1
Max	63	M	Oncology	Renal & prostate, metastatic	2012	2013	With spouse/partner	1
Dick	74	M	Oncology	Renal and bone mets	2011		With spouse/partner	2
George	69	M	Oncology	Bowel; liver & peritoneum mets	2012		With spouse/partner	3
Harry	66	M	Oncology	Lung (mesothelioma)	2013		With spouse/partner	2
April	76	F	Oncology	Ovarian	2013		With spouse/partner	3
Hannah	74	F	Oncology	Ovarian	2012		With spouse/partner	2
Nicole	48	F	Oncology	Ovarian	2008		With spouse/partner	3
Arthur	55	M	Palliative Care	Head and Neck (tonsil; liver	2009	2012	With spouse/partner	2
Winifred	74	F	Oncology	Upper GI; liver & lung mets.	2011		With spouse/partner	3
Dan	78	M	Palliative Care	Prostate, stomach & lung	2014		With spouse/partner	1
Bailey	67	M	Oncology	Prostate, bone mets.	2003		Alone	1
Roland	71	M	Oncology	Prostate, bone mets	2013		With spouse/partner	1
Patrick	78	M	Oncology	Prostate	2006		With spouse/partner	3
Graham	69	M	Oncology	Prostate, bone mets	2006		With spouse/partner	1
Richard	64	M	Oncology	Prostate, bone mets	2012		With spouse/partner	1
Ruth	74	F	Oncology	Upper GI	2010	2012	With spouse/partner	2



## Appendix 1

### Topic guide

Section	Types of questions/prompts
<b>Background</b>	Could you tell me a bit about yourself? <ul style="list-style-type: none"> <li>- Occupation</li> <li>- living circumstances</li> <li>- family</li> <li>- children</li> <li>- support system/network</li> </ul>
<b>Experience of cancer</b>	How long have you been poorly?
	Diagnosis and treatment affected day to day life
	Troublesome symptoms?
	Medication/treatment regimen
<b>Experience of pain</b>	Current experience of pain: <ul style="list-style-type: none"> <li>- sources</li> <li>- types</li> <li>- ongoing/intermittent</li> <li>- predictable/unpredictable</li> <li>- triggers</li> <li>- typical day of pain</li> </ul>
<b>Managing pain</b>	Impact on day to day life
	Type and dosage of pain medications
	Regimen for pain
	Effectiveness
	Feelings about medication
	Non-medication based strategies for pain management
<b>Involvement and communication with health professionals</b>	Current support: <ul style="list-style-type: none"> <li>- who</li> <li>- why</li> <li>- when</li> </ul>
	Accessibility
	Engagement
<b>Information, advice, and support</b>	Providing information and advice at diagnosis <ul style="list-style-type: none"> <li>- professional: generalist/specialist</li> <li>- family/friends</li> </ul>
	Other sources
	Providing information and advice about pain
	Access additional information
<b>Anything else that you would like to say?</b>	