

## Utilising out-of-hours primary care for assistance with cancer pain:

a semi-structured interview study of patient and caregiver experiences

### Abstract

#### Background

Pain is the most frequent complication of cancer and an important reason for out-of-hours (OOH) primary care contacts by patients with established cancer. Existing quantitative data give little insight into the reason for these contacts. Exploring such encounters of care could highlight ways to improve anticipatory cancer care and communication between daytime and OOH primary care services.

#### Aim

To explore the experiences, views, and opinions of patients and their caregivers who have used OOH primary care for help with managing cancer pain.

#### Design and setting

A semi-structured interview study with patients and caregivers who have utilised an OOH primary care service in Grampian, Scotland, because of pain related to cancer.

#### Method

Semi-structured interviews with 11 patients and four caregivers ( $n = 15$ ), transcribed verbatim and analysed using framework analysis and, to a lesser extent, inductive thematic analysis.

#### Results

Six key themes emerged: making sense of pain and predicting its likely course; beliefs about analgesics; priority daytime access; the importance of continuity of care and communication between all involved; barriers and facilitators to seeking help in the OOH period; and satisfaction/dissatisfaction with OOH care. Three prominent sub-themes were: patient knowledge; the influence of a caregiver on decision-making; and the benefits of having a palliative care summary.

#### Conclusion

Effective daytime and anticipatory care can positively influence OOH care. Interventions that aid patients in understanding cancer pain, communicating about pain, utilising analgesics effectively, and seeking appropriate and timely help may improve cancer pain management.

#### Keywords

general practice; neoplasm; pain.

### INTRODUCTION

Cancer incidence and prevalence rates are increasing.<sup>1,2</sup> Pain is the most frequent complication of cancer<sup>3</sup> and can lead to reduced quality of life<sup>4</sup> and increased utilisation of medical services.<sup>5</sup> Cancer pain management is frequently suboptimal despite effective treatments being available.<sup>6</sup> Complete relief of pain at the end of life is provided most frequently in hospices and least frequently among those at home.<sup>7</sup>

Pain is the most frequent symptom to prompt unscheduled medical care in oncology patients.<sup>8-10</sup> Cancer charities in the UK have raised concerns about pain management in the OOH period.<sup>11,12</sup> OOH primary care in the UK is accessed via centralised telephone systems, and provided by healthcare practitioners from a variety of professional backgrounds. The efficiency and empathy of OOH primary care services have been questioned, and delays in providing and administering analgesics have been reported.<sup>11</sup>

Little is known about the circumstances of OOH primary care use by patients with established cancer who require assistance with pain management. Pain assessment and management might be considered to be essential functions of OOH primary

care. Pain in individuals with established cancer may be an important feature of an unrelated illness. New acute pain could also be a presenting symptom of a serious complication of cancer, such as perforation of a viscus, intestinal obstruction, or pathological fracture.<sup>13</sup> It has also been argued that a portion of unscheduled pain consultations by patients with established cancer are potentially avoidable and might reflect suboptimal baseline pain management and inadequate anticipatory planning.<sup>14,15</sup> For example, difficulties in accessing in-hours care are known to predict higher use of primary care OOH services.<sup>16</sup>

This study explored the experiences, views, and opinions of patients with cancer and their caregivers who had used an OOH primary care service for assistance with pain management. Interviews explored the circumstances prompting OOH contacts relating to pain, experiences of daytime care, and participants' experiences of using OOH primary care services for help with cancer pain management.

### METHOD

Semi-structured interviews were guided by a topic schedule, which was informed by existing literature.

**R Adam**, BSc, MRCP, clinical academic fellow; **S Hall**, BSc, project researcher; **P Murchie**, MSc, PhD, FRCGP, senior clinical lecturer primary care, Centre for Academic Primary Care, University of Aberdeen, Aberdeen. **M Giatsi Clausen**, MSc, PhD, lecturer in occupational therapy, Division of Occupational Therapies and Arts Therapies, School of Health Sciences, Queen Margaret University, Edinburgh.

#### Address for correspondence

Rosalind Adam, Centre for Academic Primary

Care, University of Aberdeen, Polwarth Building, Foresterhill, Aberdeen AB25 2ZD, UK.

**E-mail:** rosalingadam@abdn.ac.uk

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## How this fits in

Pain is the most frequent complication of cancer and can result in unscheduled medical care. It has been argued that unscheduled medical attention for cancer pain can reflect inadequate daytime and anticipatory care. However, little is known about the circumstances of primary care out-of-hours (OOH) use by patients with cancer pain. This study explores the views and opinions of patients with cancer and their caregivers who have used an OOH primary care service for assistance with cancer pain management.

## Setting

The study took place in Grampian in north east Scotland. Grampian has a census population of 569 061<sup>17</sup> and is served by 89 general practices. Around 60% of the population live in and around Aberdeen city. Grampian Medical Emergency Department (GMED) provides OOH primary care, assessing around 9000 patients per month.<sup>18</sup>

## Participants

Participants were identified by searching the GMED electronic clinical record database (Adatastra) on a weekly basis for telephone or face-to-face clinical consultations, which had taken place during the previous week, and had been assigned a summary Read code<sup>19</sup> of 'neoplasm', 'palliative care', or 'terminal care'. Database searches were carried out by a GMED clinician, who read clinical notes to determine the patient's diagnosis, functional status, and the reason for GMED consultation. Potential participants were contacted on one occasion during the study period, irrespective of the number of times they contacted GMED. Patients were sent a study information pack and reply paid envelope, and were asked to contact researchers if they were interested in participating.

Included participants were English-language speakers aged  $\geq 18$  years with an established diagnosis of any cancer who had contacted GMED because of pain relating to cancer or its treatment who felt able to participate in an interview.

Patients who were thought to have entered the terminal stages of their illness at the time of the GMED encounter were excluded. This was judged from the clinical notes by the screening GMED clinician who looked for evidence of impaired consciousness, significant frailty, or explicit statements that the patient was in the terminal stages of their illness.

Participants were interviewed at a place and time of their choosing and were invited to have a caregiver or relative present. All patients and caregivers who participated provided written informed consent. The study was approved by the North of Scotland Regional Ethics Committee.

## Data generation

Semi-structured interviews were conducted according to an interview schedule. Participants were allowed to deviate from the schedule. Interviews were scheduled to last approximately 30 minutes, with flexibility to allow longer or shorter interviews according to individual requirements. Field notes were taken during the interviews, which included interesting words, phrases, or ideas that would require further clarification or probing during the interview. Interviews were recorded and transcribed verbatim. NVivo version 10 was used to assist with the management and analysis of interview transcripts.

## Data analysis

Transcripts were analysed using framework analysis.<sup>20</sup> Framework analysis gives a structured, standardised approach to the collection and management of qualitative data and allows for conceptual organisation of a priori themes prior to analysis. It was appropriate because there is some existing knowledge about palliative care in the OOH period. A thematic analysis approach<sup>21</sup> was also employed to allow for genuinely new concepts and themes to emerge inductively from the data.

The first three transcripts were coded independently and the coding framework was refined. Constant comparison was undertaken during which interview transcripts were checked following subsequent interviews to compare the experiences of all in the sample. Interviews were conducted until data saturation was reached, which was defined as two successive interviews in which no new themes were identified.<sup>22</sup> Every transcript was read in full. The authors examined the consistency of thematic coding and the credibility of the findings based on conceptual correspondence between emerging themes and coded text.

## RESULTS

Eighty-three invitations were sent between November 2013 and August 2014, and 24 responses were received. Of these responses: eight patients died soon after the GMED encounter without participating in an interview; three became too unwell

**Table 1. Demographics of patient interview participants**

Patient number	Age, years	Sex	Primary cancer site	Metastatic disease	SIMD 2012 decile <sup>a</sup>	6-fold urban-rural classification	Carer participated	Palliative summary <sup>b</sup>
1	61	Female	Breast	Yes	4	1. Large urban	No	No
2	57	Male	Prostate	Yes	4	1. Large urban	Yes	Yes
3	55	Female	Endometrium	Yes	8	6. Remote rural	Yes	Yes
4	49	Female	Colorectal	Yes	6	3. Accessible small town	No	No
5	56	Female	Breast	Yes	7	1. Large urban	No	No
6	59	Female	Melanoma	Yes	8	1. Large urban	No	No
7	53	Female	Endometrium	No	9	1. Large urban	No	No
8	47	Female	Colorectal	Yes	5	5. Accessible rural	No	No
9	72	Male	Bladder	Yes	7	6. Remote rural	Yes	Yes
10	63	Female	Breast	Yes	9	6. Remote rural	Yes	Yes
11	50	Female	Breast	Yes	6	1. Large urban	No	No

<sup>a</sup>Scottish Index of Multiple Deprivation (SIMD) 2012 ranks areas in Scotland by postcode from one (most deprived) to 6505 (least deprived) according to multiple indicators of deprivation such as employment and housing. The ranks are reported here by decile with 1 indicating most deprived and 10 indicating least deprived. <sup>b</sup>Those patients who had a structured electronic palliative care summary available at the time of the index consultation.

to take part; one patient wished to delay the interview and made further contact after completion of the study; and one patient moved out of the area. Interviews were conducted with 11 patients and four caregivers ( $n = 15$ ). Interviews with patients and caregivers took place at the same time.

Patient demographics are summarised in Table 1. Patients were aged between 49 years and 72 years (mean 56.5 years). Nine patients were female (82%) and two patients were male (18%). Primary cancer sites were: breast ( $n = 4$ ), colorectal ( $n = 2$ ), endometrial ( $n = 2$ ), urinary bladder ( $n = 1$ ), prostate ( $n = 1$ ), and melanoma ( $n = 1$ ). Ten of 11 patients had known metastatic disease. Four out of eleven patients had structured electronic palliative care summaries available for the index consultation. Eight of the eleven index consultations concerned an exacerbation of pre-existing cancer pain, while three were prompted by a new, acute pain (two cases relating to severe acute abdominal pain, and one sudden-onset back pain). Interviews ranged from 25 minutes to 74 minutes with an average duration of 44 minutes and 10 seconds. Six key themes emerged.

#### Theme one: making sense of pain and predicting its likely course

OOH contacts were precipitated by a sudden increase in pain intensity, a change in the nature of pain, or when usual management strategies failed. Participants tried to make sense of the pain in the context of their underlying illness and were keen to

understand the pain and what was causing it:

*'I don't like being in pain ... I didn't understand why, you know, if I get pain, I didn't understand why I'm getting it and what's happening so em, I kind'a worry about it in case the cancer's spread.'* (Patient 5, female)

Pain was often considered to be unpredictable in timing and duration, and this could lead to difficulties judging when to seek medical assistance. Some participants described diurnal variation, with worse pain being experienced at night. Pain at night interfered with sleep and was more difficult to manage with usual techniques:

*'It's a funny thing 'cause sometimes it's worse at night for some reason, I don't know but sometimes it's worse at night. Maybe because you're maybe no so active at night and you're thinking more about it, I don't know, but it seems to be worse at night.'* (Patient 1, female)

#### Theme two: beliefs about analgesics

Participants had concerns about analgesics, particularly about: addiction; side effects; 'masking' pain; and hastening death. Many reported a general dislike of taking medication, particularly morphine:

*'I don't like taking tablets if I don't need to, I don't, I just don't like doing things like that and obviously you hear horrible scary*

*stories about people being addicted to the tramadols ... I've never been one for taking medication when I don't need it ... I'm very independent.* (Patient 8, female)

One participant expressed an alternative positive view that morphine had helped with the emotional aspect of coping with terminal cancer:

*'Maybe if I wasn't on any medication at all because I wasn't having pain, maybe I'd be a wee bit more, oh my God, a bit more scared maybe? Maybe I'd be a wee bit more agitated ... sometimes you do have a wee kind of that feeling of euphoria that you would maybe get sometimes if you've had a glass of wine.'* (Patient 6, female)

Despite concerns about using analgesics, participants reported a pragmatic approach to using analgesics to improve quality of life:

*'Your life just becomes consumed with taking tablets to give you some sort of quality of life, but then if you didn't have pain relief then your quality of life would be rubbish really.'* (Patient 11, female)

### **Theme three: priority daytime access**

Most participants described positive experiences of accessing daytime care. Many mentioned that they were given priority access and that they were fitted in at short notice:

*'Now that they're all aware (of the cancer) it's good. They're better ... It's easier to consult with them and access them 'cause they told me any time you know that I'm worried about anything just to phone, just to phone the surgery or the nurses or whatever, so it is, it's a lot better.'* (Patient 5, female)

### **Theme four: the importance of continuity of care and communication between all involved**

The continuity of care from a single GP was important within the patient's registered practice:

*'It's just a case of feeling that you want to have some continuity with your doctor ... it's just quite reassuring to feel that you've kind of got somebody that does know where you've been and all the ups and downs that you've had and, you know, you have a, em, some sort of communication with them.'* (Patient 7, female)

Continuity was not perceived to be

as important in the OOH period when participants were happy to see any qualified practitioner. Prompt pain relief was their priority:

*'If you're phoning the out of hours and if you're in that much pain and discomfort as long as the person, the doctor you're seeing can help you, I think that's the most important thing.'* (Patient 1, female)

The importance of good communication between the OOH service, their registered practice, and in some cases palliative physicians and oncologists was emphasised. Those with palliative care summaries valued the informational continuity that they provided.

### **Theme five: barriers and facilitators to seeking help in the OOH period**

There were a number of barriers to seeking help with cancer pain during the OOH period. Participants lacked knowledge about how to initiate contact; were worried about being a nuisance; struggled to gauge the validity of their complaint; and were worried that the system was over-stretched. Rural participants were concerned that professionals had long distances to travel to them:

*'I didn't want to be a nuisance, I didn't want to be a bother, it was a Saturday afternoon ... I think I thought I maybe, it wasn't that serious, you know, there's probably somebody more serious than I ... if I've phoned and got a doctor to come to me then he's not available to go and see someone else.'* (Patient 6, female)

There were facilitators to OOH primary care use. Caregivers or significant others promoted help-seeking, aided decision-making about pain management, and often made contact with the OOH service on the patient's behalf. Patients felt empowered to use the service if they had been given specific instructions on how and when to contact the OOH service by a medical practitioner. Previous positive experiences of the service also promoted repeat use.

### **Theme six: satisfaction/dissatisfaction with OOH care**

Participants were generally satisfied with the OOH service. Satisfaction often related to the manner of the assessing practitioner and to being seen quickly. Those who expressed dissatisfaction mentioned the 'rigmarole' of telephone triaging and having to repeat information, particularly when in pain:

*'Well by the time you phone one person and you try to explain to them that you've got a growth inside you and it's bothering you and you're in a lot of pain and stuff, then they have to go and get somebody else to phone you back and you have to wait a long time ... eventually they do phone you back ... and then you're in absolute agony on the phone.'* (Patient 8, female)

There was a perception among some participants that the system was under pressure and that home visits were rationed. There was a disparity of views between those whose registered practice had shared palliative care summary information with the OOH service. Patients who had palliative care summaries bypassed telephone triaging, received priority attention, and appreciated improved informational continuity:

*'Now, they've got everything on the computer so that if everything was to happen again there's not the same rigmarole, as you might say, to go through, which you do understand, I mean they're speaking to so many different people that they can't possibly know you or remember you from previously.'* (Caregiver of patient 9, male)

## DISCUSSION

### Summary

Patients who have required OOH primary care assistance for pain relating to cancer have shared common experiences. These experiences can be considered temporally and are summarised in Figure 1. Patients

first interpret and make sense of their pain. This process is dependent on pre-existing knowledge and beliefs about pain and disease. There were potential barriers to analgesic use, including fear of addiction, side effects, and reluctance to 'mask' pain. However, it was not clear that these barriers prevented analgesic use, and patients were pragmatic about balancing concerns about analgesics with improvements in quality of life.

Where self-management strategies failed, or when pain was unusual in character or intensity, professional assistance was sought. There were barriers to seeking help in the OOH period; however, the presence of a caregiver or significant other facilitated decision-making about pain management and help-seeking. Caregivers promoted professional input and helped patients to navigate the telephone system.

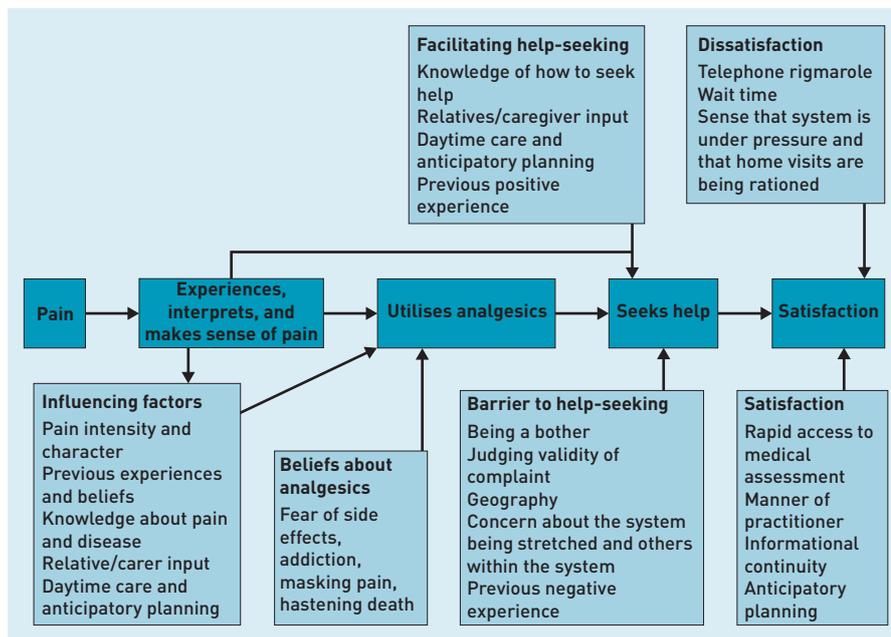
Patient knowledge and informational continuity influenced experiences at each stage of the OOH care episode. Those who had been given information about utilising OOH services felt enabled to do so and participants who had palliative care summaries had an improved experience of OOH care. They were frequently able to bypass the 'rigmarole' of telephone triaging and did not have to repeat information, both of which were sources of dissatisfaction for participants without such summaries.

### Strengths and limitations

This qualitative study has been able to recruit patients with advanced illness. Interviews with patients and their caregivers were thematically rich and participants spoke openly about their diseases and experiences. Over 8 hours of interview data were analysed by multiple researchers (investigator triangulation) who agreed on key themes within the data.

Most participants were female and <65 years, and four patients had breast cancer. However, ten out of 11 patient participants had metastatic disease and it might be argued that the presence and site of metastases in this sample is a more relevant demographic than the primary cancer type. All interviews were conducted by a single researcher who is a GP. Interviewees were aware of this professional background and this could have led to advantages and disadvantages. Participants may have felt comfortable discussing sensitive and confidential issues with a medical professional,<sup>23</sup> but may have felt less inclined to criticise health services. Clinician researchers may bring preconceptions to the interviews and data

**Figure 1. Thematic interview content as an emergent model of OOH use for cancer pain.**



analysis process. This was one important reason for investigator triangulation.

### **Comparison with existing literature**

This is the first study to have specifically investigated the nature of primary care OOH use by patients with cancer pain. Patients in this study reported negative beliefs about using analgesics. Stoicism, a reluctance to 'mask' pain, fear of side effects, and misconceptions about opioids have previously been reported in the literature and are considered to be major barriers to effective cancer pain relief.<sup>24</sup> Interestingly, participants in this study spoke openly about their concerns about analgesics, particularly morphine, but reported that they remained adherent to prescribed regimens. There was a suggestion that knowledge about the role of analgesics and a pragmatic approach to improving quality of life could counteract negative beliefs about opioids.

Patients with cancer pain experienced barriers to utilising the OOH service. This is in keeping with the findings of previous studies that have examined end-of-life care in the OOH period.<sup>25-27</sup> Barriers identified in previous studies include: anxiety about the legitimacy of need;<sup>25-27</sup> reluctance to be a bother;<sup>27</sup> negative perceptions of triage;<sup>27,28</sup> and 'unwieldy' telephone systems.<sup>28</sup> Each of these factors emerged in our study. Additionally, it was clear that caregivers played a significant role in decision-making

during the OOH period. It is likely that patients who are alone are particularly at risk of inadequate access to medical attention in the OOH period.

The importance of personal continuity of care (being known to the healthcare professional) in the OOH period has previously been emphasised.<sup>25,26</sup> Patients in our sample made a distinction between their expectations of continuity of care during routine care compared with the OOH period when patients prioritised rapid relief of pain by any qualified practitioner. Palliative care summaries enhanced informational continuity. Previous research has identified that structured summaries can reduce the risk of hospitalisation in the OOH period.<sup>29</sup> In our study, palliative care summaries also positively affected help-seeking behaviour and patient satisfaction.

### **Implications for research and practice**

Patients with advanced cancer are keen to take part in research. Effective anticipatory care and the completion of a palliative care summary can positively influence OOH care. Healthcare providers should be alert to barriers that exist to help-seeking. Interventions that aid patients in understanding cancer pain, utilising analgesics effectively, and seeking appropriate and timely help might improve the management of cancer pain.

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### **Ethical approval**

This study was approved by North of Scotland Regional Ethics committee, reference 13/NS/0075.

### **Provenance**

Freely submitted; externally peer reviewed.

### **Competing interests**

The authors have declared no competing interests.

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