

## Why do patients with cancer access out-of-hours primary care?

A retrospective study

### Abstract

#### Background

Identifying why patients with cancer seek out-of-hours (OOH) primary medical care could highlight potential gaps in anticipatory cancer care.

#### Aim

To explore the reasons for contact and the range and prevalence of presenting symptoms in patients with established cancer who presented to a primary care OOH department.

#### Design and setting

A retrospective review of 950 anonymous case records for patients with cancer who contacted the OOH general practice service in Grampian, Scotland between 1 January 2010 and 31 December 2011.

#### Method

Subjects were identified by filtering the OOH computer database using the Read Codes 'neoplasm', 'terminal care', and 'terminal illness'. Consultations by patients without cancer and repeated consultations by the same patient were excluded. Data were anonymised. Case records were read independently by two authors who determined the presenting symptom(s).

#### Results

Anonymous case records were reviewed for 950 individuals. Eight hundred and fifty-two patients made contact because of a symptom. The remaining 97 were mostly administrative and data were missing for one patient. The most frequent symptoms were pain ( $n = 262/852$ , 30.8%); nausea/vomiting ( $n = 102/852$ , 12.0%); agitation ( $n = 53/852$ , 6.2%); breathlessness ( $n = 51/852$ , 6.0%); and fatigue ( $n = 48/852$ , 5.6%). Of the 262 patients who presented with pain, at least 127 (48.5%) had metastatic disease and 141 (53.8%) were already prescribed strong opiate medication.

#### Conclusion

Almost one-third of patients with cancer seeking OOH primary medical care did so because of poorly controlled pain. Pain management should specifically be addressed during routine anticipatory care planning.

#### Keywords

cancer; pain; palliative care; primary health care; signs and symptoms; symptom management.

### INTRODUCTION

In April 2004 the new general medical services contract was introduced in the UK. For the first time, GPs could opt out of providing out-of-hours (OOH) care. By 31 December 2004, 95% of Scottish practices and 90% of English practices no longer provided OOH cover.<sup>1</sup> In Scotland, NHS Boards took over the responsibility for this provision.

In Grampian, OOH primary care cover is delivered by Grampian Medical Emergency Department (GMED). The service assesses around 9000 patients per month.<sup>2</sup> In a typical week, GMED is open for 118 hours, accounting for more than 70% of the week. Services are centralised around geographical 'hubs' and care is delivered by GPs, nurses, and paramedics.<sup>3</sup> This model of service delivery challenges traditional concepts of continuity of care in general practice.<sup>4</sup>

Continuity of care is known to be particularly important for patients with cancer and palliative care needs.<sup>5</sup> At the end of life, continuity of care has been associated with increased home deaths,<sup>6</sup> reduced emergency department use,<sup>7</sup> and improved patient satisfaction with care.<sup>8</sup> For these reasons, planned, coordinated daytime care might be preferable to OOH primary care input. As the current model of OOH primary care provision is a relatively new entity, the nature of primary care OOH service use by vulnerable patient groups is under-researched.

A number of studies have attempted to characterise the reasons that patients with cancer visit accident and emergency departments. There are a number of true oncological emergencies which can present in an acute and unpredictable fashion, for example spinal cord compression, malignant obstruction of the airway, and metabolic emergencies.<sup>9</sup> One study suggested that the proportion of 'true' emergencies in oncology patients presenting to a hospital emergency department was 26%.<sup>10</sup> Another study suggested that 32.5% of emergency department visits for patients with cancer were potentially avoidable.<sup>11</sup> Studies have consistently shown that pain is the most frequent symptom which prompts emergency department visits in patients with cancer.<sup>12-15</sup> Authors argue that emergency department visits for poorly controlled cancer symptoms can reflect inadequate routine and anticipatory cancer care.<sup>16</sup> Primary care OOH departments share some similarities with emergency departments, but there are important differences. Both departments provide unscheduled care for problems that have developed acutely, but emergency departments should be the first point of contact for the more serious and life-threatening situations where access to immediate investigations and treatments are necessary. Thus the data on cancer symptom prevalence in emergency departments are not directly transferable to the primary care setting.

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## How this fits in

In the UK, patients are unlikely to see a primary care practitioner involved in their usual care during the out-of-hours (OOH) period. The current service mainly exists to deal with urgent matters which cannot wait until the patient's registered practice re-opens. This is the first study to examine the reasons why patients with cancer make use of OOH primary care. Identifying frequent OOH contacts for potentially predictable symptoms could help to target anticipatory cancer care.

To date and to the best of the authors' knowledge, there have been no studies into the reasons why patients with cancer contact OOH primary care services. Identifying why patients with cancer seek OOH primary

care medical attention might highlight gaps in anticipatory cancer care. Targeted anticipatory interventions by daytime practitioners for frequently encountered symptoms could empower patients with self-management skills, reducing reliance on potentially less satisfactory OOH services.

This study retrospectively examined OOH contacts for patients with any established cancer diagnosis over a 2-year period. The aim was to determine the reasons for contact and to explore the range and prevalence of presenting symptoms. With the knowledge that pain was the most frequent symptom in studies of accident and emergency departments, a secondary aim of this study was to assess how patients presenting with pain were managed in the OOH primary care environment to determine which, if any, of these management strategies could be amenable to anticipatory planning.

## METHOD

### Data source

GMED contacts are recorded electronically on ADASTRA<sup>®</sup> software. Practitioners record free text information and assign a summary Read Code to each consultation.<sup>17</sup> All available Read Codes on the ADASTRA system were reviewed and the codes for 'neoplasm', 'terminal care', and 'terminal illness' as umbrella terms that were most likely to identify consultations relating to established cancer were identified. A member of GMED's administrative staff searched the ADASTRA database, filtering the results by these Read Codes for all GMED contacts between 1 January 2010 and 31 December 2011 inclusive. All patient identifiable data were removed from the search results and consultation data were saved as a Microsoft Excel<sup>®</sup> 2007 spreadsheet.

### Inclusion and exclusion criteria

Anonymous consultation notes were read and patients were excluded if, on reading the consultation details, an underlying diagnosis of cancer could not be confirmed. No exclusions were made on the basis of age. Consultations that were initiated after a call from a carer, relative, or community nurse were included. It was judged that repeat consultations for individual patients could confound the symptom prevalence. For example, a single patient might require repeated contacts for pain management, and this could artificially augment the prevalence of pain in the overall sample. Repeated consultations by the same patient were identified using the community health index (CHI) number, a unique patient

**Table 1. Patient demographics**

<b>Age, years</b>			
Mean (SD)	68.6 (13.3)		
Range	16–100		
<b>Sex</b>			
Male	466 (49.1)		
Female	484 (50.9)		
Total	950 (100)		
<b>Site of primary cancer</b>	<b>Male, n (%)</b>	<b>Female, n (%)</b>	<b>N (%)</b>
Lung or mesothelium	101 (21.7)	103 (21.3)	204 (21.4)
Upper gastrointestinal	104 (22.3)	57 (11.8)	161 (16.9)
Prostate and Urological	109 (23.4)	22 (4.6)	131 (13.8)
Colorectal	49 (10.5)	63 (13.0)	112 (11.8)
Breast	0 (0)	74 (15.3)	74 (7.8)
Not known	31 (6.7)	37 (7.6)	68 (7.2)
Gynaecological	0 (0)	67 (13.8)	67 (7.1)
Haematological	28 (6.0)	24 (5.0)	52 (5.5)
Brain	16 (3.4)	14 (2.9)	30 (3.2)
Head and neck	14 (3.0)	9 (1.9)	23 (2.4)
Melanoma	7 (1.5)	5 (1.0)	12 (1.3)
Bone and soft tissue	2 (0.4)	6 (1.2)	8 (0.8)
Other	5 (1.1)	3 (0.6)	8 (0.8)
Total	466 (100)	484 (100)	950 (100)
<b>Known metastatic disease</b>	<b>Male, n (%)</b>	<b>Female, n (%)</b>	<b>N (%)</b>
Yes	178 (38.2)	184 (38.0)	362 (38.1)
No	2 (0.4)	4 (0.8)	6 (0.6)
No specific mention in notes	286 (61.4)	296 (61.2)	582 (61.1)
Total	466 (100)	484 (100)	950 (100)
<b>Syringe driver in use</b>			
Yes	40 (8.6)	44 (9.1)	84 (8.8)
No	348 (74.7)	342 (70.7)	690 (72.6)
Not known	78 (16.7)	98 (20.2)	176 (18.5)
Total	466 (100)	484 (100)	950 (100)
<b>Strong opiate already in use</b>			
Yes	142 (30.5)	154 (31.8)	296 (31.2)
No	88 (18.9)	73 (15.1)	161 (16.9)
Not known	236 (50.6)	257 (53.1)	493 (51.9)
Total	466 (100)	484 (100)	950 (100)

identifier.<sup>18</sup> Only the first (index) consultation was included in the data extraction exercise and for final analysis.

**Table 2. Presenting symptoms of patients with established cancer who presented to GMED**

Nature of symptom (%)	Cases, n (%)
<b>Pain (30.8)</b>	262 (30.8)
<b>Gastrointestinal (20.4)</b>	
Abdominal swelling	7 (0.8)
Constipation	13 (1.5)
Diarrhoea with or without vomiting	10 (1.2)
Gastrointestinal bleeding	15 (1.8)
Nausea/vomiting	102 (12.0)
Obstructive [abdominal pain, distension, and vomiting]	5 (0.6)
Swallowing problem	22 (2.6)
<b>Neurological/psychiatric (17.5)</b>	
Agitation	53 (6.2)
Collapse	4 (0.5)
Confusion	38 (4.5)
Drowsiness	28 (3.3)
New neurological symptoms	16 (1.9)
Seizure	9 (1.1)
Twitching	1 (0.1)
<b>Respiratory (10.4)</b>	
Breathlessness	51 (6.0)
Choking	2 (0.2)
Cough	7 (0.8)
Haemoptysis	8 (0.9)
Secretions	21 (2.5)
<b>General (6.7)</b>	
Fatigue or general weakness	48 (5.6)
Poor mobility	8 (0.9)
Non-specifically unwell	1 (0.1)
<b>Fever and infection (3.8)</b>	
Fever	31 (3.6)
Discharge from a wound	1 (0.1)
<b>Multiple symptoms (3.5)</b>	
More than one presenting symptom	30 (3.6)
<b>Genitourinary (2.6)</b>	
Dysuria	2 (0.2)
Haematuria	13 (1.5)
Urinary frequency	2 (0.2)
Urinary retention	5 (0.6)
<b>Skin/soft tissue (2.3)</b>	
Painful pressure sore	1 (0.1)
Oedema	12 (1.4)
Rash	5 (0.6)
Skin reaction at infusion site	1 (0.1)
Discreet soft tissue swelling	1 (0.1)
<b>Haematological (0.8)</b>	
Epistaxis	1 (0.1)
Bruising	4 (0.5)
Haemorrhage (not GI or vaginal)	2 (0.2)
<b>Other (1.2)</b>	
Fall, metabolic (jaundice, polydipsia), vaginal bleeding	6 (0.7)
<b>Total</b>	<b>852 (100)</b>

### Data extraction

Data extracted included: patient age; sex; primary cancer site; presence of metastatic disease; use of strong opioid analgesia; reason for contact; presenting symptom(s); whether or not the contact resulted in admission to a hospital or hospice; and how pain was managed, where relevant. All forms of morphine sulphate, oxycodone, buprenorphine, and fentanyl were considered as strong opioids.

### Data handling

Each consultation was analysed independently by two authors to establish the reason for contact and principal presenting symptom(s). Both reviewers met after the data extraction exercise and compared results. Immediate consensus was reached in 862 of 950 cases. In 88 cases, consensus was reached after further discussion; 15 cases were taken to a third reviewer. Each case was settled by a two to one majority. Data were transferred to SPSS (version 19) for statistical analysis.

### Data analysis

Non-numeric data were assigned numerical codes. Descriptive statistics were calculated, namely frequencies and percentages of each variable.

## RESULTS

Nine hundred and fifty consultations by individual patients with established cancer were identified. Patient demographics are presented in Table 1. Four hundred and sixty-six (49.1%) patients were male and 484 (50.9%) were female and the mean age was 68.6 years (standard deviation 13.3). The most common primary cancer sites were lung ( $n = 204$ , 21.5%); upper gastrointestinal ( $n = 161$ , 16.9%); prostate and urological ( $n = 131$ , 13.8%); colorectal ( $n = 112$ , 11.8%); breast ( $n = 74$ , 7.8%); and gynaecological ( $n = 67$ , 7.1%). Three hundred and sixty-two (38.1%) patients were known to have metastatic disease, and 296 (31.2%) were known to be on strong opioids at the time of contact. Of 950 GMED consultations, 677 (71.3%) took place as a home visit to the patient, 212 (22.3%) were conducted as telephone consultations, and 61 (6.4%) consultations took place at a GMED centre. Eight hundred and fifty-two (89.7%) GMED contacts were due to symptoms experienced by the patient; 59 (6.2%) were prompted by a telephone call from a hospital laboratory with an investigation result; 25 (2.6%) were for administrative reasons, for example missing paperwork for inpatients in community hospitals; and 13 (1.4%) were

for technical issues with a medical device. Data on the reason for contact were missing for one patient.

More than 40 different presenting symptoms were reported (Table 2). The most frequent symptom was pain, which was the presenting symptom in 262 of 852 (30.8%) symptomatic presentations. Other frequent presenting symptoms were nausea/vomiting ( $n = 102$ , 12.0%); agitation ( $n = 53$ , 6.2%); breathlessness ( $n = 51$ , 6.0%); fatigue or general weakness ( $n = 48$ , 5.6%); and fever ( $n = 31$ , 3.6%). Of 30 patients who had more than one presenting symptom, pain was present in 27 cases. Of the 262 patients who presented with pain alone, 127 (48.5%) were known to have metastatic disease and 141 (53.8%) were already prescribed strong opioid analgesia. Of the 262 patients presenting with pain, the main primary cancer sites were upper gastrointestinal ( $n = 52$ , 19.8%); lung ( $n = 49$ , 18.7%), prostate or urological ( $n = 43$ , 16.4%); colorectal ( $n = 31$ , 11.8%), and breast ( $n = 18$ , 6.9%).

Hospital admission data were available for 948 patients and 83 of these patients were inpatients in a community hospital at the time of GMED contact. Of the remaining 865 outpatients, 696 (80.5%) stayed at home following their assessment and 167 (19.3%) were admitted to a hospital or hospice as a direct result of their assessment by the GMED practitioner.

In the 262 consultations for pain, the main pain management strategies employed in the OOH period included commencing or increasing oral analgesia ( $n = 90$ , 34.4%); administering injectable analgesia ( $n = 65$ , 24.8%); offering education or advice, particularly on how to use existing analgesia ( $n = 36$ , 13.7%); admitting the patient to hospital or a hospice ( $n = 14$ , 5.3%);

commencing an infusion of medication ( $n = 7$ , 2.7%); or adding an adjuvant medication ( $n = 6$ , 2.3%). Pain management strategies are illustrated in Table 3.

## DISCUSSION

### Summary

The most striking finding from this study is that nearly one-third of primary care OOH contacts for patients with cancer over a 2-year period were due to the patient experiencing pain. Over one-half of patients who contacted GMED due to poorly controlled cancer pain were already prescribed a strong opiate at the time of contact, suggesting that these patients had pre-existing moderate to severe pain and were being actively managed for their pain at the time of contact. Pain was a prevalent symptom in cancers which are typically associated with a poor prognosis, namely upper gastrointestinal cancers, and lung cancer.

Over one-quarter of patients who presented to GMED with cancer pain were treated with one-off injections for pain relief. Many of these patients were already on oral strong opiates. The reasons for this can only be speculated. Injectable medications generally have a rapid onset of action. There may be a perception among patients that injections are more efficacious than oral medications. A sizeable number (14.4%) of patients with cancer pain were managed with advice, education, or reassurance in the OOH period. A typical example would be a patient who contacts GMED due to cancer pain who is advised to use breakthrough medication which is already available to them in their home. It may be that delivering simple advice and reassurance are appropriate and necessary functions of a primary care OOH department. Another possibility is that there are barriers to effective self-management of cancer pain operating in the OOH period. Patient-related barriers to the use of opiate analgesics in cancer pain are well recognised and include fear of side effects<sup>19</sup> and fear of addiction.<sup>20</sup> Patients can be reluctant to 'mask' pain if they believe that pain is serving a useful role as an indicator of disease activity or progression.<sup>21</sup> Professional barriers to patient pain management have also been established and include lack of clinical knowledge about pain management,<sup>22</sup> and failure to adequately assess pain.<sup>23</sup>

### Strengths and limitations

To the best of the authors' knowledge, this is the first study to look at cancer symptom prevalence in the primary care OOH setting. The use of electronic records in the primary

**Table 3. Strategies for managing pain in the out-of-hours period**

Management strategy	<i>n</i>	%
Admission to hospital or hospice	14	5.3
Combination of management strategies	11	4.2
Commence or increase weak opioid	26	9.7
Commence strong opioid (oral route)	11	4.3
Commence subcutaneous infusion	7	3.5
Education/advice/no change in management after assessment	36	14.4
Increase oral opioid analgesia	53	20.2
Increase subcutaneous infusion	12	3.6
Injection administered without altering existing management	65	26
Addition of non-steroidal anti-inflammatory drug	6	2.3
Not known	3	1.2
Other	14	3.9
Pass to registered daytime general practice	4	1.6
Total	262	100

care OOH department has allowed a large amount of data to be collected. Data has been independently analysed by two investigators with high levels of agreement. It is important to recognise that the data were secondary data, that is, it was not initially collected for the purpose of this study. The quality and comprehensiveness of OOH records are variable. For this reason, data on patient demographics, particularly the presence of metastatic disease and use of strong opioids are incomplete. Thus the proportion of patients with metastatic disease and those taking strong opioids in this sample is likely to be an under-estimate. Availability of additional data would likely strengthen this finding that patients with cancer who access GMED often have advanced disease and pre-existing pain. The Read Codes on ADASTRA are not comprehensive and some cancer contacts will have been missed. In addition, the exclusion of repeat consultations by the same patient, while statistically appropriate, does not allow a complete picture about GMED use by patients with cancer. It would be interesting to examine the number of repeat attendances by the same patient during the study period and potential reasons for repeat attendances, but this was beyond the remit of the current study. This study cannot differentiate between symptoms caused directly by cancer and those related to anti-cancer treatments. It would have been desirable to have data on the use of cancer treatments because active anti-cancer treatment can affect pain prevalence.<sup>24</sup>

#### **Comparison with existing literature**

The results of this study are in keeping

with the current consensus that poorly controlled cancer pain is still a major problem.<sup>25</sup> The findings from this study, which utilises an exclusively primary care sample, are consistent with studies of symptom prevalence in cancer patients attending emergency departments in Italy, Canada, and the US.<sup>11–13</sup> The largest population based study took place in North Carolina, US in 2008 finding that of 37 760 emergency department visits for patients with cancer, pain was the most frequent reason for attendance (23.8%).<sup>12</sup>

The admission rates of emergency department studies are higher than those observed in the current study. A systematic review of emergency department visits for symptoms experienced by oncology patients reported a median admission rate of 58% (31–100%).<sup>14</sup> This could reflect that emergency department patients are more likely to have had a critical deterioration in symptoms. The primary care clinician has frequently been able to manage the episode by altering or adding analgesia, a strategy that might be undertaken by informed and prepared patients themselves.

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

Patient education about pain self-management with attention to any barriers that may exist to the use of opioid analgesics should be a priority in routine anticipatory cancer care. Future research is required to explore whether improved patient education and targeted anticipatory care could result in less reliance on unscheduled primary care and to characterise and quantify the potentially mutual benefits of such interventions for patients and practitioners.

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#### **Ethical approval**

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#### **Competing interests**

The authors have declared no competing interests.

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