

# The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study

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**Aim:** To explore the experiences of people with advanced cancer and/or their caregivers accessing out-of-hours care. **Background:** The organisation and delivery of out-of-hours in the United Kingdom has undergone major reforms over the past three decades culminating in the new General Medical Service contract in 2004. There are concerns around continuity of care for patients with complex needs under the new arrangements. **Design:** A qualitative interview study was undertaken recruiting patients from two primary care trusts in Southwest England. Semi-structured interviews were conducted with 28 people with advanced cancer and/or their caregivers who had recently requested out-of-hours care. Interviews were recorded, transcribed and analysed thematically. **Findings:** Two main themes were identified including the legitimacy of seeking help and continuities of care. Most participants were reluctant to seek help, finding it difficult to decide whether their needs were sufficient to contact services. The degree to which services legitimised participants' requests mediated their experiences. Distress arose when services were dismissive of their needs, whereas respondents were appreciative of clinicians who provided them with reassurance. Participants reported a lack of relational and informational continuity of care. Consulting with an unfamiliar clinician out-of-hours raised doubts in some participants' minds about the quality of care. Some participants recounted episodes in which there were problems with pain management. While the themes suggest that the delivery of out-of-hours care as a whole was not always perfect, around-the-clock access to professional sources of support and reassurance was highly valued. However, the transfer of information to out-of-hours providers remains a key challenge; participants did not understand why out-of-hours providers could not access more

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information on their medical histories given the level of computerisation within the National Health Service. The findings highlight the need to improve continuity between in-hours and out-of-hours services for patients with complex needs.

**Key words:** accessing health care; cancer care; out-of-hours medical care; primary health care; qualitative study

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## Introduction

Reducing variation in access to cancer and palliative care services by improving patient and caregiver choice in the provision, location and timeliness of services, and in the equity of provision across different patient groups, is the key goal for UK National Health Service (NHS) development (Department of Health, 2000; House of Commons, 2003–04). Effective, around-the-clock, co-ordinated care for people with advanced cancer and palliative care needs requires inter-agency working and communication (Thomas, 2000; 2003b; Gysels and Higginson, 2004).

Consistent with these aims, a major policy goal is to ensure the continuity of health care. ‘Continuity’ is a multi-dimensional concept, which has been defined in many different ways (Freeman *et al.*, 2001), although three major components are consistently identified. Informational continuity is the use of information of past events and personal circumstances to make current health care appropriate for each patient. Relational (or ‘personal’) continuity relates to the ongoing therapeutic relationship between patient and clinician, which allows previous experiences to shape both the current and future care that are provided. Management continuity is defined as a consistent and coherent approach to the management of a health condition (including the actions of staff and the settings in which they operate) that is responsive to a patient’s changing needs (Haggerty *et al.*, 2003).

Out-of-hours primary care services have undergone major reorganisation over the past three decades in response to successive UK government policies (National Audit Office, 2006) culminating in the implementation of the new General Medical Services contract in 2004 (NHS Confederation & British Medical Association, 2003).

Out-of-hours primary care services are now commissioned by local primary care organisations. As providers, out-of-hours services are operationally independent from daytime acute and primary care services. As such, out-of-hours staff do not have routine access to full NHS records (informational continuity), nor is it realistic to expect the clinical staff to have long-standing, personal relationships with the patients who contact the service (relational continuity). This has led to concerns with regard to the continuity of care for people with complex needs in the out-of-hours period, and particularly those with palliative care needs (Thomas, 2000; Murray *et al.*, 2004; Worth *et al.*, 2006). Recent health policy and guidance documents have highlighted the need to improve teamwork and inter-agency communication between out-of-hours primary care and daytime services (Department of Health 2006; Lakhani *et al.*, 2007) to ensure that all aspects of continuity are addressed.

The general public calling out-of-hours have expressed concern about the urgency with which their cases are handled and the amount of time they have to wait for a call back or home visit (National Audit Office, 2006; Egbunike *et al.*, 2008). A qualitative study (Richards *et al.*, 2007) found that service users were often anxious about calling the service, in part due to concerns about whether their call was appropriate, combined with difficulties in conveying the nature and urgency of their problem. Once medical care is accessed, patients are generally complimentary about the health professionals’ skills and the quality of care received (Richards *et al.*, 2007; Egbunike *et al.*, 2008). These findings mirror those of earlier studies reporting on the experiences of people with palliative care needs and their caregivers (King *et al.*, 2004; Worth *et al.*, 2006). However, given their advanced needs,

relational continuity may assume particular importance, with the lack of access to familiar sources of professional help and support being felt keenly by patients and their families (King *et al.*, 2004). Indeed, many such patients report that they prefer to wait to speak to their own doctor rather than calling an 'impersonal service' (Worth *et al.*, 2006).

While studies have explored the experiences of people with palliative care needs seeking out-of-hours care in the United Kingdom, data collection took place before 2004 when the latest changes to out-of-hours primary care were implemented. This qualitative study therefore builds on existing work, by exploring the experiences and decision-making of people with advanced cancer and their caregivers when accessing out-of-hours care under the new arrangements.

## Methods

The study was approved by the North and East Devon NHS Local Research Ethics Committee (05/Q2102/24) and the appropriate NHS trusts.

### Study design

A qualitative study using semi-structured interviewing was conducted. People with advanced cancer and their caregivers were involved in the study design. Six hospice patients and caregivers gave feedback on the content of participant recruitment letters and information sheets. A user group, comprising 10 patients and caregivers attending a hospice day care unit, discussed their experiences of using out-of-hours services and helped inform the interview topic guide.

### Settings and sampling

People with advanced cancer with palliative care needs and caregivers were sampled from two geographically and socio-economically diverse primary care trusts (PCTs, Plymouth and South Hams & West Devon). At the time of data collection, although residents in each trust had access to broadly similar generalist and specialist services (Box 1), there were some notable exceptions. Twilight District Nursing was available only in Plymouth, and operational hours of treatment centres varied between trusts based on local demand. The Gold Standards Framework (GSF)

for community palliative care (Thomas, 2003a) was being implemented in both areas.

Purposive sampling was used to maximise variation in age, gender and clinical histories, and the range of out-of-hours services accessed. Potential interviewees were deemed eligible if they met the inclusion criteria (Box 2).

### Participant recruitment

Given the vulnerability of potential participants, the recruitment and data collection process required careful consideration (Lee, 1993). We involved clinical teams to minimise distress to potential participants, asking clinicians to approach only those individuals who might be sufficiently well enough to participate in a short interview within the next month. Participants were recruited through seven general practices, three community nursing teams, two acute hospital wards (haematology and oncology), two specialist palliative care nursing teams and a hospice. Recruitment continued until the data were analysed to be saturated. Clinical teams approached potentially eligible participants, providing them with written information about the study and a reply slip to return to the research team if the individual was interested in taking part. A researcher telephoned potential participants to answer any questions they might have and to arrange an interview as soon as possible after the reply slip was returned. Written consent was obtained from participants before the commencement of the interview.

### Data collection

Each person was telephoned by the interviewer the day before the interview to ensure that they were well enough to participate in the interview. Given the advanced nature of participants' health problems, to minimise participant fatigue and burden, the interview was strictly limited to a maximum of 1 h, and in most cases lasted no more than 40 min. Within this context, a semi-structured interview approach was adopted to ensure that core topics of interest were covered. A topic checklist was developed through literature reviewing and user feedback, and used to guide the interview. Topics included peoples' awareness of the range of out-of-hours services available and

**Box 1 Overview of clinical teams offering out-of-hours support**

Team	Type of service	Out-of-hours availability <sup>a</sup>	Clinically trained staff <sup>b</sup>
NHS Direct	Telephone advice	Evenings and weekends	Registered nurses
Ambulance Service	Telephone advice and home visit	Evenings and weekends	Paramedics, ambulance crew
Minor Injury Unit of the Hospital	Telephone advice and treatment clinics	Evenings and weekends	Registered nurses
Oncology Ward of the Hospital	Telephone advice	Evenings and weekends	Registered nurses, on-call doctors
Haematology Ward of the Hospital	Direct admission	Day-time on weekends	Registered nurses, on-call doctors
Emergency Department of the Hospital	Telephone advice and direct admission	Evenings and weekends	Registered nurses, on-call doctors
Hospice Inpatient Unit	Telephone advice	Evenings and weekends	Registered nurses, on-call doctors
Hospice Community Nurse	Telephone advice and home visiting	Day-time on weekends	Clinical nurse specialists
District Nursing	Telephone advice and home visiting	Day-time on weekends	Registered nurses
District Nursing Twilight Service <sup>a</sup>	Telephone advice	Evenings all week	Registered nurses
Out-of-hours Primary Care	Telephone advice, treatment centres and mobile units	Evenings and weekends	General practitioners, nurse practitioners

NHS = National Health Service.  
<sup>a</sup> A mapping exercise captured service availability in 2003–04. Twilight Nursing was only available in Plymouth Primary Care Trust (PCT). The services listed were all still available in 2006. Current (2010) service provision varies as the two PCTs have been restructured and existing services modified.  
<sup>b</sup> Other health-care staff (eg, health-care assistants) with less extensive clinical training may be available.

their reasons for, and experiences of, using these services when requesting help for urgent, unplanned health needs. The interviews were conducted by two researchers. The socio-demographic characteristics and living circumstances of participants were noted.

**Data analysis**

The interviews were audiotaped and transcribed verbatim. The data were anonymised (using fictitious initials) and analysed using the method of constant comparison (Strauss and Corbin, 1998). Three transcripts arising from

early interviews were analysed by two independent researchers in order to develop provisional categories against which data could be indexed. The emergent themes were identified based on similarities of experience and then organised into a smaller number of overarching categories. Discrepant data and negative cases were sought to check the robustness of the emergent themes. The thematic analysis of data also ran alongside recruitment. Consequently, the coding of later interviews was informed by earlier ones, so that emerging issues could be explored. Summaries of each case were written describing the services used and the main themes emerging from their account

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## Box 2 Inclusion criteria for patients and caregivers of patients

1. Participants were eligible if they:
  - Had advanced cancer (ie, were receiving palliative treatment for a malignancy) or were a caregiver for such a patient
  - Were aged  $\geq 18$  years
  - Had accessed an out-of-hours health-care service within the past year
  - Were capable of at least 30 min of interview
  - Were able to give consent to the study
2. Patients/caregivers were excluded if they had:
  - A severe communication difficulty, which might limit their ability to participate
  - Dementia or severe learning difficulties
3. Caregivers were eligible if they:
  - Lived with or were in regular contact with the patient
  - Were not paid professional caregivers
  - For caregivers who were bereaved, the patient had died not less than three months ago or more than 12 months ago

in relation to an individual's repeated experiences of accessing out-of-hours care. These summaries avoided the fragmentation of peoples' accounts by maintaining the relationship between their views and their use of services, and have been used in similar settings (King *et al.*, 2004). As a means of checking the reliability of the analysis, the themes and categories from the summaries were compared with those from the original coding of the transcripts, revealing a high level of congruence.

## Results

### Sample

Patients and caregivers were recruited between January and June 2006. Thirty-six patients and caregivers were approached and 23 (64%) agreed to participate. Between agreeing to participate and the interview taking place two patients died and one became too unwell to participate. Thus, 20 interviews were conducted with 28 people (13 patients and 15 caregivers). The sociodemographic characteristics

and living circumstances of participants varied considerably (Table 1), with the exception of ethnicity (all participants were White British).

### Study findings

Over half the calls to out-of-hours services, for which a reason was given, were due to pain management (Table 2). Our participants had contacted out-of-hours services many times (Table 3), and by far the most commonly accessed service was out-of-hours primary medical care; consequently, most peoples' comments relate to this service.

Two overarching categories were identified relating to the legitimacy of seeking help and continuities of care.

#### *Legitimacy of seeking help*

This category reflected the feelings of vulnerability experienced by participants after their doctor's surgery had closed, and their doubts about whether their condition was serious enough to merit a call. In all, 12 out of the 16 participants who discussed this theme reported delay in seeking help. The decision to call the service was seriously considered, as interviewees did not want to 'bother' anyone.

... night times it's ten times worse, you know. (...) you are very vulnerable, you know. You don't want to phone the doctor just to chat, that's for sure ....

(Mr LM)

Well I think you would find that almost anybody sat here, if it's a night time call, it's the uncertainty they feel in themselves, because I mean, you don't want to be upsetting anybody on their weekend if you don't have to, but if you are sitting there in pain and it's gone on several hours, you feel as if you have got to ring somebody, to do something about it just in case it does go on the whole weekend.

(Mr TA)

It is possible that people who live alone delay longer than others, possibly because there is no one to confirm the legitimacy of their needs. Where the person did not live alone, it was often the caregiver who finally took control and made the call, or encouraged the patient to do so.

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**Table 1** Characteristics of interviewees ( $n = 28$ )

Interviewee <sup>a</sup>	Patient's age (years)	Patient's gender	Patient lived alone?	Caregiver identified	Caregiver's age (years)	Caregiver's gender	Caregiver's relationship
Mrs AS	70	Female	Yes	No	–	–	–
Mr and Mrs BL	69	Male	No	Yes, interviewed	66	Female	Spouse
Mr and Mrs CT	51	Female	No	Yes, interviewed	52	Male	Spouse
Mr and Mrs DF	61	Female	No	Yes, interviewed	60	Male	Spouse
Mr and Mrs EM	61	Female	No	Yes, interviewed	61	Male	Spouse
Mr FP	Deceased	–	No	Yes, interviewed	68	Male	Spouse
Mr GS	76	Male	Yes	Yes, not interviewed	–	–	–
Mrs HT	Not interviewed	–	No	Yes, interviewed	43	Female	Daughter
Mrs IB	Deceased	–	Not reported	Yes, interviewed	51	Female	Daughter-in-law
Mr JK	Deceased	–	No	Yes, interviewed	66	Male	Spouse
Mr KL	96	Male	Yes	No	–	–	–
Mr LM	Deceased	–	No	Yes, interviewed	68	Male	Spouse
Mrs MP	Not interviewed	–	No	Yes, interviewed	66	Female	Spouse
Mr and Mrs NS	58	Female	No	Yes, interviewed	Not given	Male	Spouse
Mrs OB	77	Female	Yes	No	–	–	–
Mrs PD	Not interviewed	–	No	Yes, interviewed	69	Female	Spouse
Mrs SB	52	Female	No	Yes, not interviewed	–	–	–
Mr and Mrs TA	71	Male	No	Yes, interviewed	68	Female	Spouse
Ms WA	39	Female	Yes	No	–	–	–
Mr RS and two caregivers	75	Male	Yes	Yes, two caregivers present at interview	66 and 67	Male and Female	Friends

<sup>a</sup> All initials are fictitious. Interviews may be conducted with individual (patient or caregiver) or with pairs of respondents (eg, patient and their caregiver).

**Table 2** Reason for calling (were given)

Initials <sup>a</sup>	Pain	Infection	Chemotherapy related	Post-operative complications	Miscellaneous <sup>b</sup>
AS	1				2
BL	1				1
CT	1 + many				1
DF	9	1			2
EM	2				1
FP		1	2		1
GS	1				2
HT			1		4
IB	1 + few				2
JK	3				
KL	1				1
LM	1 + few				
MP		2		2	
NS	1		1		
OB	5				1
PD		2			1
RS	2				1
SB				2	
TA	2				1
WA	2				
Total	>33	6	4	4	21

<sup>a</sup> Not everybody gave a reason each time they called the out-of-hours services.

<sup>b</sup> This category includes less common reasons for calling the service. Examples include breathing difficulties (three instances), diarrhoea or constipation (two instances) and problems with prescriptions (two instances).

...my wife was dead against calling anybody. (...) Yes, she really was. 'Don't bother them with that', you know, and err, yeah, she didn't like me calling at all but I had to for my sake, you know.

(Mr LM)

There were six cases in which participants felt that the out-of-hours doctor had been dismissive of their concerns, thus denying the legitimacy of their calls. In all of these cases, the participants were very distressed by their experiences.

I felt, I felt a nuisance. You know, as if I had called him out and his time is far too precious to be dealing with us.

(Mrs HT)

...'Here am I, a GP administering an injection. Nurses can do that. You don't need a doctor to do this.' And I think the point perhaps he was really saying is that there may be some serious doctory things going on that he ought to be attending to,

not applying – so I said to him, 'Well we don't have[nursing] cover'.

(Mr JK)

In the case of Mrs HT, she needed the doctor to acknowledge her fear that her father was dying, but this had not happened. Instead, she felt so affronted by his attitude that she said if he ever returned, '*I would not let him in*'.

Although less common, there was one incident in which legitimacy was confirmed. Mrs AS had continued to experience pain following operations for breast cancer. She rang the out-of-hours service and the doctor who visited suspected the cancer had returned and arranged a hospital admission the following day. The cancer had returned and Mrs AS was impressed that her pain had at last been correctly diagnosed and was delighted with the out-of-hours doctor's manner.

While there were clearly specific instances recounted of problems accessing care from out-of-hours primary care services, this should be balanced against the many positive accounts of using out-of-hours services. These accounts are

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**Table 3** OOH service use

Initials	OOH primary care			NHS Direct	Hospital				Hospice	District nurses		Specialist community nurses		Own GP	Patient total
	HV	TA	TC	TA	Ambulance	A & E	Ward TA	Admitted to ward	TA	HV	TA	HV	TA	HV	
AS	1	1							1						3
BL			1						1		1				3
CT	1 + many	1 + many	1			1 + few			1	1					6+
DF	1 + many	1 + many	1	1					1	1	1 + many		1 + many		8+
EM	2				1										3
FP		1					2			1		1		2	7
GS	1									1					2
HT	1	1	1		1		1	1							6
IB	1 + many									1		1			3+
JK	2	1			1		1		1		3				9
KL		2													2
LM	2	1		1 + few				1							5+
MP		1	2	1	1					1					6
NS	1		2			1	1								5
OB	2			2	2										6
PD	2		1	1	1										5
RS	2				1										3
SB			1				1	1							3
TA		2				1									3
WA	1	1													2
	20+	14+	10+	6+	8	3+	6	3	5	6	5+	2	1+	2	>90

OOH = out-of-hours; NHS = National Health Service; GP = general practitioners; HV = home visit; TA = telephone advice; TC = treatment centre visit; A & E = Accident & Emergency department.



much less detailed than stories of problematic encounters, and tended to be general reflections on the experience as a whole.

I was kind of dreading it and I did think to myself, oh no, I am ringing on a Sunday, I don't know what's going to happen, am I going to have to wait around for hours? And it wasn't the case, it was very, I was really pleased with them, with the treatment.

(Mrs SB)

I think what we'll say was that our whole experience was a good one and that erm, if we needed to use it then we were very confident about it.

(Mr FP)

There's nothing worse than feeling that you are on your own and there's no support and like it's the unknown. When you know that you can pick up the phone and at the other end are experienced professionals and they are like tuned in and that in a matter of minutes you can have assistance. That makes all the difference.

(Mr EM)

### *Continuities of care*

While theoretical models clearly identify three components with regard to the continuity of care, in participants' accounts the different aspects (informational, management and relational) were interwoven. Difficulties in accessing help out-of-hours were experienced because familiar sources of professional support were unavailable (relational continuity), and the process of making an out-of-hours call was seen as lengthy and complicated due to a lack of informational and management continuity.

I would have loved to have picked up the phone and say to my health centre, 'Look Doc, [wife's name]'s got this problem again.' and he would have known. (...) And then we had to fill this form in and, over the telephone. 'Who is the patient, where do you live, what's the concern?' erm and maybe some other details as well, I can't remember clearly, but it was always the same, 'Who is your doctor, what's your health

centre?' You know, blah blah and 'OK, a doctor will contact you'. And I remember thinking, I'm vulnerable, my wife is in pain and we want a service and, and I have to ring up this person – 'The doctor will contact you'! What, tonight? Tomorrow?

(Mr JK)

I think it was just the thought that, how do we do this? It seemed a long way round like, you know. (...) I think it was all the explaining that you would have to do. You didn't have anybody that you could ring up and say, erm, 'I am ringing up for (husband's name)' and they said, 'Ah yes'.

(Mrs TA)

People calling more than once in an evening or several times in quick succession were puzzled as to why they had to repeat the same information.

But each time you have to repeat exactly what has been (said) the week before. It's as though they haven't got the records there, they've got no visibility of what's gone on beforehand, you've got to tell a new story each time.

(Mr CT)

Concern that out-of-hours primary care services are unable to access patients' full, 'in-hours' medical records held in either primary or secondary care services was raised in 12 interviews. Several participants were concerned that the out-of-hours doctors were 'at the mercy of the patient, how accurate they are' (Mr EM), which, in turn, raised safety issues with regard to medications and the ability to relate their often complex medical histories.

I know the first thing the doctor will ask you over the phone at [GP out-of-hours service] or indeed when the doctor calls, is, 'What medication is she currently on?' But logistics or logic states that the more likely a person is to be long term poorly, more likely they are to be older, more likely they are to be not quite as sharp as they were when they were younger and more prone to forgetting things.

(Mr EM)

While ideally participants desired relational continuity, that is, the ability to consult with a clinician

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who knew them and their medical history, most understood that this was unlikely to occur. Acknowledging this, most participants expected the clinician to be able to access a summary of their complex medical history. This could only be achieved by a combination of managerial and informational continuity. Several interviewees could not understand why, given the availability of computer technology, the out-of-hours services were unable to access their medical history.

I mean our own GP obviously knows Dad's case inside out, but there must be a way where the [out-of-hours] doctor can access at least a recapped version of what's wrong with him ... you would think he had to tap into his computer and access everything but, you know, he went solely on what I told him when we went in. So that to me was strange.  
(Mrs HT)

I mean with everything being computerised now I would have thought that if I, if I phone up [GP out-of-hours service] then the person on the other end of the line should be able to go tap, tap, tap, whoof and everything is there.  
(Mr DF)

On the other hand, Mr TA felt that it was unrealistic to expect out-of-hours doctors to be able to access the medical history of everyone who called. However, his point was that this made it all the more important for out-of-hours doctors to show the interpersonal skills necessary to understand their patients' needs and to provide much needed reassurance.

Well I don't see how they can ever cover, having everybody's information who happens to phone up that particular night can they? So I mean that's got to be too difficult. What you really want them to do, is to show some sort of understanding and try to give you some advice and help... least you feel as if someone has now got your case in hand and you won't be left to wander the moors as it were.  
(Mr TA)

When seeking out-of-hours care, the particular needs of people with cancer were discussed in

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12 interviews, with most participants indicating that they valued seeing a doctor who had some expertise in cancer and/or palliative care, particularly when undergoing active treatment. Two people remarked that out-of-hours general practitioners (GPs) do not usually have the necessary expertise. Mr EM remarked, '(...) *of course they can only generally, I guess, be GPs or like, not specialists in a particular field*', whereas Mrs HT said, '*Very nice doctors but, they, I don't know, they're general.*'

Perhaps because of this, several people preferred to seek out-of-hours help from the oncology ward, especially if they were having chemotherapy. While this approach would certainly ensure access to the relevant expertise, by adopting this strategy, patients are also maximising the relational and managerial continuity in their care.

He [the oncologist] knew what he was talking about and that immediately gives you reassurance. You know, that you knew that he was an oncology doctor and you thought, well yeah, he knows what, and you know I always got it wrote down what I take so I just passed it to him and he knew.

Erm, that's the only people I can think of that would know enough about the situation. (...) Just basically because it's the cancer ward and I found, you know, they were really, really good, you know, when I was going into the chemo and stuff like that.  
(Ms WA)

Difficulties in accessing pain relief out-of-hours were discussed in six interviews. A key issue was the speed with which this could be arranged given the severity of pain experienced. In some accounts, individual services or clinicians failed to respond as rapidly as the patient or caregiver would have liked. For example, Mrs CT had to call the out-of-hours primary care service frequently at one stage because of pain. Waiting for the doctor to visit was distressing for both her and her husband:

You know you get to, because I am sort of at the side looking at the pain and I am the one sort of getting stressed from it, she's suffering the pain and I am stressing, and I am

thinking do I get in the car? Do I create more pain? You know, it's all these sorts of things that go through your mind.

(Mr CT)

One participant described inadequate care planning upon discharge from hospital. Mrs NS had been given morphine to control her pain during a three-week hospital admission but was discharged with only paracetamol for pain relief. As she said, 'A few hours out, I was climbing the walls'.

Others described problems when more than one provider was involved in an episode of care, consistent with difficulties in both informational and managerial continuity. For example, Mrs DF had been 'screaming literally with the pain in my back' and 'banging my fists against the wall with the pain' so her husband called the out-of-hours doctor and was advised to give his wife another painkiller. After a couple of hours, the pain had returned and Mr DF called the out-of-hours doctor again. This time the doctor visited them at home and arranged for an ambulance. However, they waited 4.5 h for the ambulance to arrive. On ringing the ambulance headquarters Mr DF was told that the doctor had not stated that it was an emergency.

## Discussion

### Summary of main findings

Although a range of different sources of support was available, the most frequently used and commented upon service was that of out-of-hours primary care.

We found that participants often felt vulnerable at the time of making out-of-hours calls and many were reluctant to contact such services until they were sure that it was appropriate. The need for reassurance permeated participants' accounts. The degree to which the service legitimised the request for medical help was paramount in mediating participants' experiences of care, with distress resulting when the service challenged the appropriateness of their requests. The finding of reluctance of participants to call for help out-of-hours is consistent with research conducted before the most recent service reorganisation with patients with palliative needs and their caregivers (King *et al.*, 2004; Worth *et al.*, 2006) and other service users within the general population (Richards *et al.*, 2007). Similar

difficulties have been reported in a study of service users contacting the NHS Direct (Goode *et al.*, 2004). Goode *et al.* (2004) argue that the UK health service promotes individual responsibility for health, with patients conceptualised as consumers and a discourse of citizenship used to encourage consumers not to over-exercise their rights by being 'greedy'. The spectre of being considered a 'time-waster' is very powerful and patients feel the need to justify visiting the doctor and to assess whether their demand is legitimate. Goode *et al.* (2004) noted that, 'only responsibility for others seemed to override reflexive considerations of "deservingness": an explicit sense of entitlement to health and welfare services surfaced when adults were trying to access care on behalf of partners, elderly parents or children' (p. 223). This is certainly mirrored in our findings, as our participants were much more confident and forthright about the legitimacy of calling for help on behalf of others than they were for themselves.

Continuity of care was also important to our respondents. While theoretical models clearly identify three components (informational, management and relational) of continuity, in our participant's accounts they were interwoven. Relational continuity in out-of-hours care is increasingly unlikely and it has been suggested by others that informational and management continuity supplemented by good communication may enhance the experiences of patients with palliative care needs (Worth *et al.*, 2006). We found a lack of both relational and informational continuity was described in relation to out-of-hours primary care; doctors did not personally know the patient nor appeared to have access to their medical history. Mechanisms already exist to enhance informational continuity, such as the use of hand-over forms ('special messages') supporting the transfer of enhanced clinical data sent from the in-hours services to the out-of-hours team (Thomas, 2000). Special messages are one component of the GSF for community palliative care, which had been implemented to varying degrees in our sampling area at the time of data collection. Data from an audit study in a different area found that special messages have not been widely implemented (in only 13.1% of palliative care patients' records; Burt *et al.*, 2004). Although we have no way to verify whether special messages

had been generated for our interviewees, our data suggest that there is a widespread perception that out-of-hours services had insufficient information about them. Consistent with this, the Royal College of General Practitioners has recently called for the wider use of methods to ensure that urgent care providers are aware of patients with complex needs (Lakhani *et al.*, 2007).

In the absence of relational and informational continuity, the quality of a clinician's consultation skills assumed vital significance in supporting the legitimacy of the request and providing reassurance. While many participants would have preferred to see a familiar doctor, this preference did not appear to be born out of sentimentality. The concern was more about the quality of their medical care as it could be difficult to accurately convey complex information. There are two underlying explanations about informational continuity from a service perspective. The first is that the clinicians involved must take sufficient detail about the patient to ensure that each episode is safely managed, although at times this can seem frustrating or repetitive to those seeking help. New developments in the out-of-hours computer systems now allow clinicians to more readily identify patients who have previously called and their records can be more easily linked. However, the comprehensive adoption of computerisation by British GPs may have led patients to expect similar levels of technology throughout the NHS. Currently, there is no integration of primary care, hospital and out-of-hours primary care records.

In terms of management continuity, several qualitative studies have asked patients, caregivers and professionals to identify the essential elements of generalist care for dying people (Curtis *et al.*, 2001; Borgsteede *et al.*, 2006). Important aspects identified include the accessibility, approachability and technical skills of the doctors, with doctors who are willing to listen and explain things to patients in an unhurried manner being particularly valued. Our participants reported some of these aspects, but were particularly appreciative of professionals who had some expertise in cancer and/or end-of-life care.

Pain and symptom management is core to good quality end-of-life care (Curtis *et al.*, 2001; Borgsteede *et al.*, 2006), and out-of-hours access to controlled drugs is a key challenge for general practice and nursing teams (Thomas, 2003a). This

resonates with our findings as the most common reason cited by our participants for calling out-of-hours primary care was pain management. Furthermore, negative experiences of care often coincided with an episode of poorly controlled pain.

Our initial aim was to explore people's choices and experiences of using out-of-hours care since the implementation of the new GP contract. This qualitative study cannot answer whether people's experiences have changed as a consequence of the new arrangements. However, when comparing our findings with the existing literature (King *et al.*, 2004; Worth *et al.*, 2006), the apparent stability of some of the main themes (with regard to help-seeking and continuity) suggests that the new arrangements have made little impact. Even our newer findings, such as the ever-increasing expectations with regard to computer technology, have no plausible basis arising from the new contract.

### **Strengths and limitations of the study**

Recruiting participants at the end of life is difficult and some selection bias is inevitable. Nevertheless, the proportion of those who were approached and who refused to participate was low (36%) suggesting that our methods were appropriate and sensitive. Our sampling strategy resulted in participants with varied disease histories and sociodemographic characteristics. However, although consistent with the Devon population profile (98.7% 'White' in 2001 census), the lack of ethnic diversity suggests that our findings may be less applicable to such communities.

Our two overarching categories, relating to the legitimacy of seeking help and continuities of care, emerged from the data after applying rigorous analytical methods. However, by necessity we used a semi-structured approach to interviewing due to the vulnerability of study participants and the need to limit the length of interviews. Thus, the two emergent categories may have arisen, in part, due to the structure imposed on the data collection by the topic guide, and the different themes that may have arisen had a less structured approach to data collection been possible.

Although the interviews raised distressing issues, people were keen to talk about their experiences. Recruitment took place in two PCTs, both of which use the same out-of-hours primary care provider, and therefore, some findings may

be service-specific. However, with over 95% of UK providers using the same ADAstra<sup>®</sup> computer system (2010) and with no linkage between their records and that of other NHS services, the concerns over informational continuity have much wider applicability.

Finally, while many of the themes are characterised by details of negative episodes, the case-study approach identified that many participants also recounted positive experiences (although in much less detail) relating to other times they had contacted the same service. While the delivery of out-of-hours care may not always be perfect, it is clear that the knowledge and reassurance provided by access to professional sources of support around-the-clock was highly valued by our participants.

## Conclusions

Patients with advanced cancer and their families need reassurance and support when accessing out-of-hours care due to their concerns with regard to the legitimacy of their requests. Ensuring continuity of care for patients with complex needs remains challenging. The need to improve the transfer of information to out-of-hours providers is a key target for both in-hours and out-of-hours teams. However, given that mechanisms already exist to facilitate the transfer of information between teams, further research is urgently needed as to why they remain under-used.

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