

Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals

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ABSTRACT

Background

New out-of-hours healthcare services in the UK are intended to offer simple, convenient access and effective triage. They may be unsatisfactory for patients with complex needs, where continuity of care is important.

Aim

To explore the experiences and perceptions of out-of-hours care of patients with advanced cancer, and with their informal and professional carers.

Design of study

Qualitative, community-based study using in-depth interviews, focus groups and telephone interviews.

Setting

Urban, semi-urban and rural communities in three areas of Scotland.

Method

Interviews with 36 patients with advanced cancer who had recently used out-of-hours services, and/or their carers, with eight focus groups with patients and carers and 50 telephone interviews with the patient's GP and other key professionals.

Results

Patients and carers had difficulty deciding whether to call out-of-hours services, due to anxiety about the legitimacy of need, reluctance to bother the doctor, and perceptions of triage as blocking access to care and out-of-hours care as impersonal. Positive experiences related to effective planning, particularly transfer of information, and empathic responses from staff. Professionals expressed concern about delivering good palliative care within the constraints of a generic acute service, and problems accessing other health and social care services.

Conclusions

Service configuration and access to care is based predominantly on acute illness situations and biomedical criteria. These do not take account of the complex needs associated with palliative and end-of-life care. Specific arrangements are needed to ensure that appropriately resourced and integrated out-of-hours care is made accessible to such patient groups.

Keywords

palliative care; cancer care; out-of-hours medical care; qualitative research; primary health care.

INTRODUCTION

Cancer patients spend about 90% of the last year of life at home and at least two-thirds of this is 'out-of-hours' when, despite careful planning, unexpected deterioration may occur.^{1,2} ('Out-of-hours' is defined as evenings, weekends from Friday evening to Monday morning, and public holidays. This reflects the working hours of many primary care and palliative care staff, although GP surgeries' opening hours vary within the working hours of 8 am and 6.30 pm.) Reorganisation of out-of-hours primary care services in the UK has fundamentally changed the way in which patients and carers access care. Since the late 1990s, general practice cooperatives have been the dominant model of service provision. GPs have evaluated these positively, although the response from patients and other professionals is more varied.²⁻⁷ More recently, the establishment of centralised services (NHS Direct in England and Wales, NHS 24 in Scotland) presents a new model of

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24-hour telephone advice that will be the single point of access to all out-of-hours services, even in rural areas. The intention is to benefit patients and carers by offering simple and convenient access to advice and effective triage, so that appropriate care can be delivered quickly and efficiently.⁸ Responsibility for health care is being transferred from GPs to local primary care organisations, which are currently setting up new unscheduled care services.

Patients are now unlikely to receive care out-of-hours from a doctor who knows them. There has been a progressive shift in the locus of care from the home and local general practices to more distant emergency clinics or telephone advice.⁹ The impact on patients for whom continuity and home visiting are particularly important will be greater.^{1,10} It may contribute to some admissions to hospital or hospice, and might affect patient choice about place of death.^{1,11} An understanding of the needs and experiences of palliative care patients and their carers is essential to ensure that out-of-hours care is effective as well as efficient. This is particularly true when service reorganisation is driven mainly by policy and provider imperatives, rather than patient and carer needs.

We aimed to explore with cancer patients and their carers the process of deciding whether to call out-of-hours services, and to describe what their needs were and how they perceived the services they received. The views of key professionals about out-of-hours service provision were also obtained, allowing us to collate user and provider perspectives and make recommendations about service design.

METHOD

Recruitment

We selected three general practice out-of-hours cooperative areas (urban, semi-urban and rural) from across Scotland, to represent a range of settings and service arrangements. The local research ethics committees and primary care trusts approved the study. The cooperatives were studied sequentially, between January 2002 and April 2003, before the introduction of NHS 24.

In each area, we identified a range of patients with advanced cancer who had contacted the out-of-hours service, using a combination of reports from out-of-hours service administrators and examination of records. Their GP was telephoned and asked to invite the patient to participate. If the patient agreed to be contacted, an information sheet was posted, and the researcher telephoned the patient or carer to answer any questions, and arrange an interview. Consent was gained from all participants at the time of interview. This recruitment process meant

How this fits in

Studies of community professionals and the retrospective experiences of patients and informal carers have suggested that palliative care is often provided suboptimally during the majority of the week that is 'out-of-hours'. Current reconfiguration of UK health services, to create a separate emergency care provision accessed via a centralised system, poses significant challenges for people with complex needs, such as palliative care patients. An in-depth, qualitative approach has enabled us to describe the multiple fears and uncertainties faced by palliative care patients and their carers, regarding the legitimacy of their needs, continuity of care, and the nature of services available. Professionals share concerns about how to ensure information transfer is optimal, and being able to access a range of support, and describe the tensions associated with delivering both acute and palliative care out-of-hours.

Table 1. Recruitment and attrition details

	Totals
Dates of recruitment	February 2002 to April 2003
Number of GPs contacted	118
Number of patients contacted by researcher	57
Number recruited ^a	36

^aReasons for non-recruitment were mainly: the patient's death; the patient was too ill; the patient was unable to give informed consent; or the patient was admitted to hospital.

Box 1. Overview of patient/carer dataset.

Interviews with patients and carers (*n* = 36)

- ▶ 17 patients alone
- ▶ 4 carers alone
- ▶ 15 joint patient/carer

Focus groups

- ▶ 1 group hospice patients (*n* = 7)
- ▶ 7 groups carers (*n* = 48)

vulnerable patients were not contacted inappropriately. Recruitment was complex, as expected in this patient group, with many patients too ill, or dying between the out-of-hours episode and the researcher making contact (Table 1).

We convened eight focus groups — one of patients and seven of carers — from the three study areas, to gain a broader range of perspective about out-of-hours services. In particular, this enabled non-users to be sampled. Recruitment was through local hospices, a hospital-based users' group, and carer involvement workers. Box 1 shows the patient/carer dataset. Key professionals were recruited to reflect local variation in provision of care across the three study areas.

Box 2. Patient/carer interview guide

1. Could you start by telling me about your call to the out-of-hours service?
 - ▶ the background to the call
 - ▶ the decision to make the call
 - ▶ what happened during the call?
 - ▶ what happened after the call?
2. Could you give comments and suggestions about how the out-of-hours services might be improved?
3. Are there any other matters you wanted to raise?

The extended version of this guide is available as supplementary information.

Data generation: interviews and focus groups

Patients and carers were interviewed at home by an experienced researcher, separately or together if they wished, as soon as possible after the out-of-hours contact. The majority were interviewed within 2 weeks, although a small number were delayed by up to 30 days if the patient had been admitted to hospital or if the patient had died. The study aimed to explore participants' experiences and understandings, and employed qualitative methods to facilitate an interactive interview relationship and the progressive development of areas of enquiry. The interview guide (Box 2) was used flexibly according to the patient's ability to participate. The interviews lasted 30–90 minutes. Participants in the focus groups were encouraged to raise the issues about out-of-hours services that they perceived to be most pertinent to them. Key professionals were interviewed by telephone.

Analysis

All focus groups and the majority of interviews, where patients consented, were tape recorded and transcribed with field notes. The emergent themes and the research questions formed the basis of the coding strategy. Analysis was facilitated by use of the qualitative computer package, QSR NVivo, and constant comparative method.¹² The data from each area were analysed as a case study, then the patient and carer data as a whole, and the focus group data separately, before complete synthesis. Regular review and discussion of the evolving themes by the multidisciplinary steering group contributed to data synthesis and interpretation.

RESULTS

Thirty-six patients were recruited, and interviews

were conducted with 32 of them. Four had died or become too ill to participate, so only their carers were interviewed. Interviews were also conducted with a total of 19 informal carers, and 50 professionals. The patients ranged from people currently receiving palliative oncology treatment to those who were terminally ill. Many had used the out-of-hours service on several occasions. The patients' ages ranged from 30 to 91 years; 17 were male and 19 female. Twenty-five patients had received a GP visit, six a district nurse visit, five had attended the out-of-hours centre, and three received telephone advice only. Three patients contacted the service more than once about a problem that continued despite an earlier intervention. The eight focus groups involved seven patients and 48 carers. Key professionals interviewed included the patient's GP, district nurses, out-of-hours service personnel, palliative care specialists and hospital staff.

Seeking help out-of-hours: patients' and carers' perspectives

Patients and carers generally cited pain, vomiting (sometimes associated with chemotherapy), breathlessness, and a range of other physical symptoms, not all cancer-related, as their reason for contacting the out-of-hours service. The need for reassurance, information, advice and comfort was equally clear. Nursing services were often requested for wound and catheter problems. Uncontrolled symptoms and sudden changes in the patient's condition caused patients and carers considerable fear and anxiety:

'It was so alarming and the onset was so sudden that I was really quite afraid, actually I thought my last hour had come, the pain was very intense.' (Patient interview 9, Coop B.)

Patients and carers were generally reluctant to contact out-of-hours services. When they did, their views of the response they received ranged from being very unhappy to highly satisfied. Factors that assisted patients and carers in seeking help, and those that hindered them in gaining the care they needed are summarised in Box 3 and used to structure presentation of the key themes.

Helpful factors

Patients and carers described a range of factors that aided their access to out-of-hours services and which resulted in outcomes they perceived as helpful. Learning how to manage the system helped to overcome anxieties and enabled patients and carers to obtain the service they wanted:

Box 3. Factors that helped and hindered patients and carers in seeking help out-of-hours.

Helpful factors

- ▶ Learning to manage the system
- ▶ Previous positive experience
- ▶ Clear, accessible contact information
- ▶ Encouragement to use services
- ▶ Effective triage
- ▶ Being known to the out-of-hours service
- ▶ Staff with good communication skills

Hindering factors

- ▶ Anxiety about the legitimacy of their need
- ▶ Previous negative experience
- ▶ Not knowing who to call
- ▶ Reluctance to 'bother the doctor'
- ▶ Perceiving triage as challenging
- ▶ Not knowing the person on the phone
- ▶ Inability to give a clear account of problem

'I was fortunate I think when I had my collapse that my wife phones now and there is no way anybody will put her off. She's determined she wants somebody to come and see me and come hell or high water they will come.' (Patient, Focus Group, Coop B.)

Encouragement to contact out-of-hours services if they were worried was helpful. Some people described being given clear, easily accessible information about who to contact and under what circumstances, by their own professionals such as GPs, specialists or community nurses:

'At first I used to get myself in a state — what a shame bringing them out ... I was very much reassured by them when I apologised, they said "no apologies, that's why we're here".' (Patient interview 6, Coop A.)

Experienced users were more likely to see triage as helpful. They were often known to the service and had access to fast-tracking, so they could speak to a doctor or nurse quickly without having to repeat their story several times or wait for someone to call them back. This was usually because information highlighting the patient's needs had been sent to the out-of-hours service by their own practice:

'The last time we phoned, they knew. My husband's name and number are obviously

flashed to them or they have something that triggers their knowledge that they must attend to him quickly.' (Carer interview 9, Coop C.)

Good communication, particularly empathic responses from call handlers, from the person performing triage, and from the GP or nurse, created positive experiences of care. For some people, this over-rode their preference for personal continuity of care:

'I suppose it does matter a little bit in your mind that it's not your own doctor ... but once he arrived, he did away with that worry immediately. I would say he was effective and efficient, very pleasant and confident, so he made us feel confident too.' (Patient interview 7, Coop B.)

Many patients were anxious to avoid admission, but most of the eight who were admitted considered it appropriate in the circumstances:

'I was very clear to them "look I don't want to go into hospital" ... [but] they need to admit you because they think there might be an infection there. And that's fair enough.' (Patient interview 8, Coop C.)

Hindering factors

Many factors that patients and carers perceived as barriers to obtaining out-of-hours care were associated with their anxieties, uncertainties and lack of information. Most of them found deciding whether to call the doctor or not extremely difficult. Although influenced by individual variations in personality and help-seeking behaviour, uncertainty was pervasive: about the seriousness and urgency of the problem, whom to contact, what the response might be, and the legitimacy of their need:

'Well, it's very difficult, if you want a doctor, from 6 pm or later. They do not want to come out. They want you to wait until the following morning, unless you're really ill and it's very difficult to know if you're really ill or not, you know? And it's like you have to judge, you know, am I really ill, do I need the doctor? I think I do, but the doctor doesn't seem to think I do.' (Patient, Focus Group, Coop A.)

People's anxieties were compounded by knowing that others were often perceived as abusing the system by calling with minor needs, and they expressed reluctance to be labelled as demanding or difficult, and fear of embarrassment if their needs were not found to be major or urgent:

'I know I would rather suffer the dreadful pain than bring the doctor out because I'm too embarrassed and because I know he's annoyed at having to come out.' (Patient, Focus Group, Coop A.)

Some patients and carers lacked information about the services or forgot in the heat of the moment, and some blamed themselves for not getting help:

'I think I was so worked up myself that I just forgot what I could have done.' (Carer interview 10, Coop B.)

Many said they preferred to wait until the morning, so they could speak to their own GP or specialist nurse, who knew them and their history, instead of using an impersonal service. Some described low expectations of out-of-hours services, based on media reports or hearsay. Others were concerned that a doctor who does not know them might be more likely to admit the patient to hospital:

'If they do come out and see it's a cancer patient with so many complications they go "hospital". Before even checking the patient out a lot of times they just go, "hospital", because they are too scared to deal with that patient, with all the tablets and the conditions they've got.' (Carer, Focus Group, Coop B.)

Some patients and carers found it difficult to summarise their needs, and some felt that it was a waste of time answering questions when they needed a home visit. A carer, whose husband died later that night, said:

'He [the GP] said "what's the matter?" I said "my husband is needing assistance of some kind or other", I said "his breathing's dreadful and he's sliding down the bed and his feet's beginning to go over the bottom of the bed, I said he's not a well man". Well I did'nae start, I possibly should have started giving him all the details but I said by the time I started giving them all the story, they could be up.' (Carer interview 10, Coop C.)

The triage process was sometimes perceived to be hostile. Being asked questions they felt ill-equipped to answer, such as 'Is it an emergency?' or 'Do you need medical attention?' by call handlers, or repeatedly telling the same story to different people led many to feel their credibility was being challenged:

'I do feel that they come across as unsympathetic on the phone, like they're checking you out all the time, whereas they should be trying to be as helpful as possible.' (Carer interview 5, Coop B.)

'I feel I've got to explain it to the person that answers the phone first of all, then I have got to explain it to the nurse that you speak to, then I've got to explain it all to the doctor that comes out.' (Patient interview 7, Coop B.)

Previous negative experiences had a significant effect. An abrupt response, perceived reluctance of GPs to visit, or being requested to attend the primary care centre instead of receiving a home visit made people reluctant to use the service again:

'If something drastic had happened here that night, I would have ended up being collected in a box ... it has really put me off phoning them ... I feel safer with the hospital ... I feel I would just get in or get an ambulance, bypass the out-of-hours.' (Patient interview 1, Coop A.)

'One of the things I found difficult at that time is they asked "is your husband able to come down to the centre?". Really I don't think my husband should have been faced with that and I don't think I should have been faced with the decision.' (Carer interview 9, Coop C.)

Some carers perceived their needs as unmet because of a lack of nursing support and respite care:

'When I asked the district nurse if I could have a night nurse when my husband was at that last week of his life, they said "oh well no it'll take 4 days to organise".' (Carer, Focus Group, Coop C.)

Key professionals' perspectives

Professionals suggested that finding the time to address palliative cancer care needs effectively is important, but challenging, in the context of providing a generic out-of-hours service. Problems accessing a range of other health and social care resources out-of-hours compounded this.

Providing good palliative care

Continuity of care was seen as the main casualty of the new arrangements, although these were perceived as having benefits for GPs:

'... in terms of palliative care I would say it was worse for patients and better for doctors ... inevitably there has been a loss of continuity

that's really quite important ... I think it was a better deal than it is now, perhaps having an unfamiliar and almost certainly quite stressed and rushed doctor.' (GP3, Coop C.)

'I think to do really good palliative care, it's not good to be on call 24 hours a day. It's about giving them the tools to do the service well.' (GP1, Coop A.)

Improved communication between in-hours and the out-of-hours services, particularly provision of up-to-date information from daytime to out-of-hours services, was viewed as crucial in improving triage, decision making and continuity of care:

'If we've got hand-over information that's a big help initially when we're speaking to the patients on the phone in order to triage the calls and make a sensible decision about what we do.' (GP1, Coop B.)

'I've been guilty of it in the past myself, not updating things when they should have been, because I think it's very easy to send in the form to begin with and then think that's it.' (GP4, Coop B.)

Professionals suggested that effective multidisciplinary organisation and planning should include: early referral to out-of-hours nursing services; giving patients and carers written information about who to contact, and encouraging them to use out-of-hours services; addressing carers' needs for support; and ensuring that drugs are available. Some suggested using an integrated care pathway. Professionals also acknowledged that not all palliative care needs are predictable:

'You can't always know what's going to happen. People deteriorate very suddenly. People you thought were quite stable go off very quickly, and family who you thought were coping quite well suddenly think they can't do it any longer and it's a crisis.' (GP1, Coop B.)

Providing palliative care in the context of a generic out-of-hours service

Palliative care calls were variable. Calls were infrequent, but could be demanding and time consuming. GPs gave palliative care a high priority, but working in a generic service with limited staff and time often meant that acute conditions, such as chest pain, had to take precedence:

'For carers and for me the nightmare is to have to be involved in someone who is terminally ill

when you're extremely busy and have a whole lot of other calls stacked up, so we lack time to sit down and give people the time to explain what is going on in a way that is not hurried, and then to make sure that whatever solution is needed is the one that is appropriate.' (GP2, Coop B.)

Lack of time to assess and address needs was acknowledged by some doctors to be a contributory factor in admission out-of-hours:

'The easiest thing to do is to send them in — that solves the problem. You don't have to go back that way, you know they will be taken care of ... You are moving from one patient to the next very quickly in a busy night; these sort of patients need a bit of time.' (GP1, Coop B.)

Availability of resources

An adequate district nursing services out-of-hours was regarded as essential. The variability between services at different times and in different areas was viewed by GPs and community nurses as a major inequity:

'It just depends too much on where you live, what nursing service is available. We need a dedicated, rapid response district nursing service for palliative care, and not just for people with cancer, so we have more time to spend with patients and families.' (Community palliative care nurse, Coop B.)

Social care, overnight care and carer support from statutory or non-statutory services were a major problem, particularly at short notice, and again most notably in rural areas:

'The main problem is that there are not sufficient services for people to be cared for at home ... there may be a breakdown in carers because they don't get enough respite.' (Community hospital nurse, Coop C.)

The introduction, in all three areas, of a 24-hour community pharmacy scheme for palliative care, was generally praised. Although demand for specialist palliative care out-of-hours was mostly perceived as insufficient to warrant provision of a visiting service, access to telephone advice from specialist staff was a universal requirement for both GPs and community nurses.

DISCUSSION

Summary of main findings

This study makes explicit the barriers experienced by palliative care patients and their carers when

accessing care. These reside in their uncertainties, and in service responses, which are designed for acute medical rather than palliative care needs. Concerns about getting effective help are shown to contribute to patient and carer anxiety and may influence admissions. Although patients' call sheets recorded predominantly physical reasons for contacting the out-of-hours services, the data clearly show the complexity of decision making for palliative care patients and their carers, and the influence of psychosocial factors in determining their needs. We also heard accounts of excellent care, enabling a number of aspects of good practice to be delineated. The importance of good anticipatory care, particularly provision of information to patients and carers along with regularly updated handover forms sent to out-of-hours services, was identified as key by both patients and professionals. Professionals described the barriers to achieving individualised patient care and the problems posed by competing priorities, but saw potential for improvements through an expansion of other out-of-hours resources, particularly nursing and supportive care.

Strengths and limitations of the study

In order to make recommendations for effective service development at a time of significant change in a major component of primary care, it is essential to capture the views of service users and to integrate these with professional perspectives. We gained detailed accounts of people's experiences soon after they had used an out-of-hours service, and were able to access a vulnerable group of patients in an acceptable way. Recruiting patients at the end of life is difficult, so attrition and some selection bias are inevitable.^{13,14} It is important to find out why people do not access services, and we attempted to do this through using focus groups.

Comparison with existing literature

Previous studies have suggested that good anticipatory care, particularly provision of information to patients and carers about sources of help out-of-hours, and what to expect from services, helps maintain care at home and manage patients' and carers' expectations of services.^{4,15} Accessibility of GP and nursing support has been identified as a major component of effective out-of-hours care.^{16,17} Current out-of-hours service organisation, particularly the triage process with its protocol-based approach, does not fit well with the holistic ethos of end-of-life care. GPs and district nurses want 24 hour access to specialist palliative care advice on symptom management and medication use.^{1,2,11,18} Access to palliative care drugs

and advice via a community palliative care pharmacy network is a quality standard in Scotland.¹⁹ Out-of-hours district nursing support is a crucial and much appreciated component of effective care.²⁰ However, shortages continue to be identified, and services are not available on an equitable basis nationally.^{21,22}

To some extent, the anxieties experienced by patients and carers in this study are applicable to patients generally. Many other patients are anxious about the legitimacy of their needs, and find out-of-hours care impersonal or difficult to access.^{4,9,10} Certain groups of patients, however, might be considered to have special needs, such as palliative care patients, people with severe mental health problems and frail older people and their carers, suggesting that these findings have wider implications for out-of-hours services. Patients with advanced non-malignant illnesses may have different perspectives and needs from patients with cancer, as well as being less likely to have a terminal phase of their illness identified and having access to fewer services.^{23,24} They do, however, share the need for end-of-life care pathways which address continuity of care and choice, incorporating out-of-hours provision.²⁵ For palliative care patients, the possibility of offering choice about place of care and place of death is fundamentally influenced by out-of-hours provision.²⁶ Carers of palliative care patients face particular stress, with carer anxiety identified as a common reason for admission out-of-hours.^{1,21}

Implications for clinical practice

The findings from this study can contribute to current service redesign. Information that encourages appropriate use of out-of-hours services needs to be made accessible to all patients and carers. Primary care professionals and community palliative care specialists share responsibility for advising patients and carers when and how to seek help out-of-hours. Practices and primary care organisations need to develop and audit effective systems of patient information management and transfer. These could be included in quality standards. Reviewing the way calls are handled by NHS Direct/NHS 24, in addition to their factual content, offers opportunities for communication difficulties to be highlighted and included in staff development. Algorithms specific to palliative care might aid NHS 24 in assessing such patients' needs.

Effective out-of-hours community palliative care requires an integrated, multidisciplinary service able to respond to planned and acute needs. Continuity of care may be personal, informational or managerial, the latter implying a consistent and

coherent approach responsive to the patient's changing needs.²⁷ In the context of current primary care provision, personal continuity of care is increasingly unlikely to be provided out of hours, but our data suggest that informational and management continuity, supplemented by good communication, may suffice. Equitable access to a range of health and social care professionals and support staff across the UK may well demand additional resources, particularly for district nurses. Partnership working with non-statutory palliative care providers could be enhanced. Services must be provided on the basis of need not diagnosis, for people on all illness trajectories.²⁸ Specialist palliative care telephone advice to unscheduled care services, including access to a consultant in palliative medicine, may need to be delivered through extended rotas in areas where there is a shortage of specialists. In areas with a high call rate, consideration could be given to having a reserve clinician available to allow out-of-hours GPs more time for these small but vulnerable groups of patients and carers.

Supplementary information

Additional information is available online at <http://www.rcgp.org.uk/journal/supp/index.asp>

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Ethics committee

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Competing interests

The authors have stated that there are none

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