

A review of an out-of-hours telephone support service for palliative care patients and their families

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There has been a growing trend in the United Kingdom (UK) and elsewhere in the developed world toward care of the terminally ill at home. The World Health Organization (WHO) (2004) states that good quality care toward the end of life should be recognized as a basic human right, and the choice to die at home in comfort and tended by family members should be part of that right. Such a choice, it is claimed, is capable of bringing psychological and physical benefit to the patient. It should not be forgotten, too, that one of the drivers of the shift is also the cost savings accrued from keeping terminally ill patients out of expensive inpatient facilities.

Being terminally ill or caring for someone who is terminally ill can be a lonely experience away from the busy world of the clinical ward. Stories of demanding patients, and emphasis on consumer rights can mask the high numbers of patients who are actually very undemanding and even somewhat reluctant to 'trouble' professional medical staff whom they perceive as being overloaded and very busy (Hanartty, 2000; Kim and Schulz, 2008). While many family members are keen to care for their loved ones at home, to give them their choice of place of death, the burden of care on them can be considerable at a time when they are already experiencing emotional distress (Kinsella et al, 1998). In public health terms we also know that a variety of psychological outcomes flow from the stresses experienced by home-based palliative caregivers, including anxiety, depression, reduced self-esteem, fatigue, feelings of isolation, and somatic health problems, leading to their own health consequences (Cheng et al, 1994; Kissane et al, 1994).

Such burdens and worries can be even greater when daytime staff 'clock off' and terminally ill patients and their carers are left to face the darkest hours of the night with only emergency care services to call upon. Given that most out-of-hours GP services in the UK are now contracted out, the likelihood is that a medical call-out will be attended by someone who does not know the

Abstract

Offering people at the end stages of life the chance to die in their own homes is acknowledged good practice and can bring comfort to terminally ill people, but it can also be a hard choice to sustain. Carers may find it extremely difficult to cope with the emotional ordeal of losing a loved one and dealing with the medical problems that are involved but their voices are infrequently heard. This study reports an evaluation of an out-of-hours service operating in one primary care trust in north east England, and focuses on the use of a telephone support service, which backed up domiciliary visits by specialist palliative care nurses. Interviews, focus groups and an open-ended questionnaire were carried out with 27 participants. Results revealed that staff, patients and carers appreciated being able to telephone the service (reactive). In addition carers felt particularly well supported by the service staff who proactively telephoned them on an agreed basis as part of the highly individualized telephone monitoring scheme. Such services support the call for the creation of a whole system approach for both palliative care patients and their carers.

Key words: Palliative care ● Telephone service ● Out of hours ● Carer support ● Home support ● End-of-life

patient and his/her medical history and may not themselves be expert in palliative medicine. The consequence is an inevitable increase in expensive emergency admissions to hospital and the disappointment for the patient and carer of having 'failed' to keep the sick person within their home environment. Campbell et al (2005) note that an essential component of good palliative care for terminally ill patients and their carers is to have ready access to professional advice and support out of hours, a position endorsed by a variety of other agencies (Cancer Relief Macmillan, 2001; National Institute for Health and Clinical Excellence (NICE), 2004; Department of Health (DH), 2008).

A recent article by Yardley et al (2009) suggested a framework for good practice in order to meet the NICE (2004) guidelines for provision of a 24-hour advice line. This article reports on an out-of-hours telephone service that provides both reactive and proactive support.

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Table 1. Participants

Method	Participants	Number of participants
One-to-one interviews	Patient	6
	Carers (including former carers)	8
Focus groups	District nurses	4
	Macmillan team	6
Open-ended questionnaire	General practitioners	2
	Out-of-hours emergency care service	1
Total		27

Background

The study reported here was part of an evaluation of an out-of-hours support service created for palliative care patients and their carers in a primary care trust (PCT) in the north east of England. The service aims to support patients who wish to be cared for in the terminal stages of their illness in their own homes. The service is distinguished from many others by using specialist palliative care nurses on call to homes and patients. The service runs from the local hospice itself and consists of qualified nurses and health-care assistants (*Figure 1*). The scheme also has a bank service for qualified nurses and health-care assistants to provide cover for annual leave and illness.

The service has a telephone contact system, with proactive and reactive facets. A reactive element means that after office hours the service receives telephone calls from health professionals, patients or their carers in need of attention or advice. Callers can request a home visit from a specialist nurse to deliver treatment, change drug dosage, deliver pain relief and so on. The service also contacts patients at an agreed time and interval. The proactive telephone calls from the

out-of-hours service to the patient occur at an agreed period such as every day, week or month at a certain time that is mutually convenient to both the patient and the service. The topic and length of discussion varies from either a quick check-up and update to a longer conversation and reassurance.

Similar service developments have been described elsewhere (Campbell, 2005; Yardley et al, 2009), but have not revealed the views of patients and carers on the operation of the service. The authors set out to discover what impact an out-of-hours telephone service had on the perceived quality of care of palliative care patients and their carers. Heyland et al (2006) have referred to 'our nascent understanding of what quality care means to patients and their families' and comment that patient and family perspectives are surprisingly lacking. Jo et al (2007) state that though an essential principle of palliative care is that the patient and his or her family comprise the unit of care (Ferris et al, 2002), the majority of studies on this topic often neglect to examine both perspectives on the care-giving experience. Some of this reluctance clearly arises from a reticence about researching patient and carer views at what might be seen as a sensitive time (Addington-Hall, 2002), but Kendall et al (2007) have highlighted how critical it is for service development in this area to be guided by user voices. A recent scoping exercise for the NHS Service Development Organisation (Higginson et al, 2007) concluded that the development of carer perspectives was a priority in future research on palliative care.

Methods

Qualitative in-depth interviews (and some self-completion surveys) were conducted by members of the research team to gain the views and opinions of service users, carers and health professionals (*Table 1*). The hospice sister approached patients in the first instance and invited them to

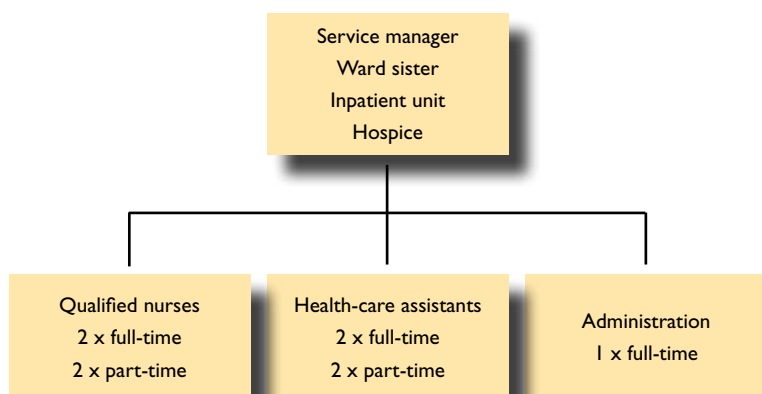


Figure 1. Organizational chart

contact the researchers, following which a meeting was set. Carers and former carers were sent letters of invitation to take part in this research by the hospice staff. Health-care staff were approached through their clinical leads.

All of the interviews were carried out by the same researcher, providing consistency of questioning. Participants were all over the age of 18 years and were able to give informed consent. Ethical approval was sought and obtained from an internal university research governance and ethics committee and from the National Research Ethics Service.

Analysis

All interviews were recorded and transcribed with the permission of respondents (with one exception where notes were taken). Thematic content analysis was used as recommended by Bernard (1991) and Braun and Clarke (2006). For this process, the researchers immerse themselves in the data and extract the emerging themes that are then reviewed and refined.

Results

Reactive telephone call service to out-of-hours service

An audit of the calls received by the telephone service indicated that the service had been used by health professionals and patients and their carers. The service received telephone calls from various health professional groups such as the Macmillan team, GPs and hospital staff and their use of the service remained relatively constant or

even declined, for reasons that are not clear. As can be seen, however, in *Figures 2 and 3*, a large number of telephone calls to the service were made by patients or their relatives and their use of the service has certainly increased over time.

Relatives and/or carers made the greatest number of calls to the service (52%) over the duration of the service to date (November 2004–October 2006) followed by the district nursing team (17%).

Patients living on their own found the possibility of being able to telephone the service in the middle of the night reassuring. Patients and their carers were given the telephone number of the service and were encouraged to call the service if they felt they needed to. For one terminally ill woman it eased the burden of needing to phone and disturb her carer—her daughter—who worked during the day and needed her sleep. It is hoped, therefore, that the use of the service assisted in maintaining the patient's independence:

'Yes, I'm too independent. I find it very hard to cope with the fact that I used to be the carer for my daughter and now the shoe is on the other foot. That I have to give up looking after my home and give that job to someone else is difficult.' (Patient 2)

The service provided is not just for the sole use of the patients. Several patients and carers commented on the positive aspects of having the out-of-hours talk to the carers. Carers felt this was positive and welcome. One carer commented that

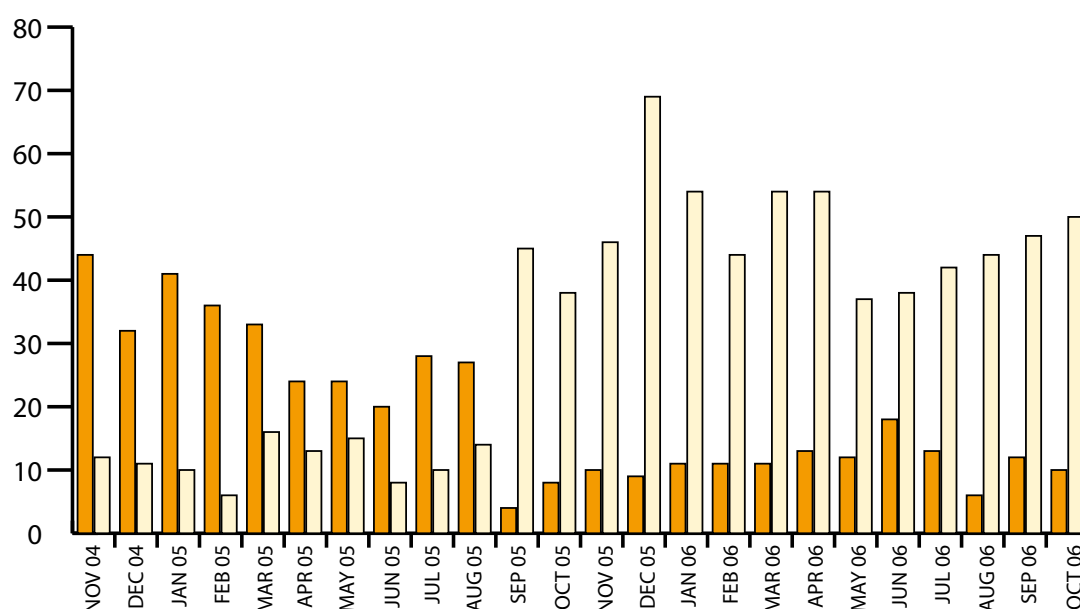


Figure 2. Number of phone calls made to the out-of-hours service between November 2004 and October 2006

he was pleasantly surprised that the service was there for him as well:

'Yes, they knew my name. I picked up the phone and they said 'is that XX?' and I said 'yes'. "This is the out of hours" ... I thought, "how did they know my name?" [laughs]. 'I never did find out how they knew my name ... it was nice to know that they went to the trouble of finding out your name ... not just impersonal people just phoning you up because it is their job. You felt that they were taking an interest and they know what your problems are to an extent' (Carer 7)

Proactive telephone call service to patients

The proactive telephone call service was one of the options available to patients and carers. For one patient receiving chemotherapy after long and complicated surgery, out-of-hours staff used to phone her every night, and, on occasions, deliver prescriptions. For this one patient it was her only contact with the service, as she did not use the home visiting element of the service:

'I've never actually had to have any of it [out-of-hours home visiting] ... they used to say

every night "if you need it, just call" ... but I've never actually had to do that ... I've had contact with them all the time 'til just after I've finished my chemotherapy.' (Patient 5)

Nevertheless this patient valued this service as she said:

'I don't know if I could have managed ... it was so helpful for someone to ring me up every night [to ask] if I needed any help.' (Patient 5)

A number of interviewees reported to find the service approachable. Whereas patients had previously not liked to 'bother' doctors with their problems, the out-of-hours service was seen as informal and easy to talk to:

'You don't feel [you are] necessarily disturbing them, at least they are there for that purpose ... whether you are getting them up or not I don't know ... I didn't know how it is run, but I don't feel like I am getting them out of bed so I felt better about phoning them up in the early hours of the morning.' (Carer 7)

'I find that the out-of-hours are so understanding, because they have the experience. I can feel

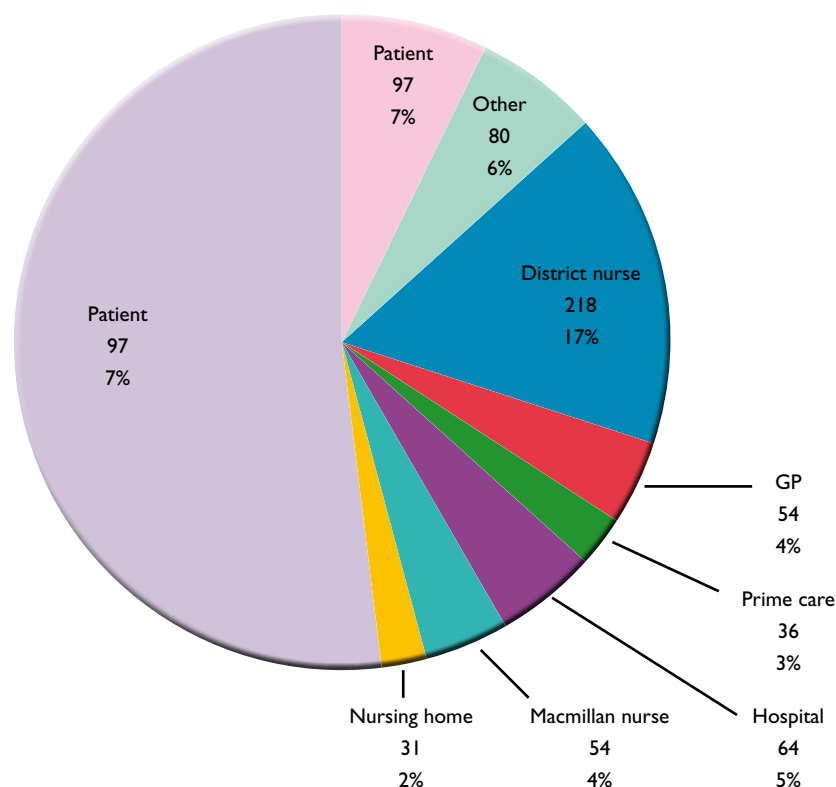


Figure 3. Number of phone calls to the service

the difference between an out-of-hours nurse or hospice nurse and the practitioners ... You feel as if they have the time and experience; they don't rush you or push you away.' (Carer 6)

Another patient and carer emphasized how important it was to maintain regular contact and commented:

Patient: 'Anyway they phone us.' Carer: 'They phone every Sunday night.' Patient: 'Every Sunday night, 8.30.' Carer: 'They are the only place that hasn't forgotten you. You know what I mean? In between all the chemotherapy, your appointments etc., there are times when it goes quiet and there's nobody there, but they [the out-of-hours service] are always there because they always phone up.' Patient: 'Your safety net is them.' Carer: 'They always phone up and they will always come out ...' (Patient 3 and Carer 6).

Health professionals also discussed the proactive nature of the service and flexibility of the out-of-hours staff in working with the patients and their carers—and taking into account their views and needs. One such example of this is the service organizing with the patient and his or her carer the time of a check-up telephone call:

'I think people value the flexibility of the service as well. They could have a domiciliary visit if needed but initially someone may contact them to find out what they want—should it [the check up 'phone call] be every other night or once a week so that it's not forced on them.' (Macmillan team)

Discussion

A number of tools have been recommended by the government to improve the quality of end-of-life care in generalist settings and these are currently being adopted in many areas (e.g. the Gold Standards Framework), to improve palliative care provided by primary care teams, the Liverpool Care Pathway to improve care at the very end of life, the Preferred Place of Care Plan (now known as the Preferred Priorities of Care plan), an advanced care plan. With the advent of the Preferred Place of Care Plan and the recognition that most people in the UK would prefer to die at home (DH, 2008) health services need to adjust the way they deliver palliative care. Alterations to services are not as simple as extending current provision of community care to include palliative care. Day time community nursing services do an admirable job, but the majority of the time in a

week lies outside normal working hours, meaning that patients, their families and carers are potentially left to cope on their own. Consequently a need has arisen to ensure that there are services around to support both patients and carers and/or family members throughout the week.

This study aimed to address the need for provision of health professionals out of hours. The study found that the service was well used by health professionals and by patients and carers. The largest number of telephone calls to the service was made by relatives, followed by patients and district nurses. The number of phone calls increased over time and this was mirrored by the increase in the number of referrals made to the service. The results of this study support the findings of Campbell et al (2005), where the majority of calls to the service also came from carers and/or family members.

Patients valued and appreciated both proactive and reactive telephone calls. The possibility of being able to call on the advice of the palliative care practitioner not only resolves immediate clinical problems but also allows the family to handle better the emotional pain of the situation (Guigou, 2002).

Jo et al (2007), in their Canadian study of spousal caregivers, found that many carers did not receive adequate emotional support, and noted difficulties in communication with formal providers, and poor coordination of care among services. In contrast the carers in the current study reported feeling supported. The authors believe that a great deal of this support and the sense of a coherent approachable service was conveyed through the medium of the proactive phone call, as well as out-of-hours providing a skilled and rapid response to any emergency clinical situations that developed.

Conclusion


Carers and family members were impressed that the out-of-hours nurses would talk to them, as well as to the terminally ill patient. Up until that point they had felt that on many occasions their questions, concerns and needs were ignored by a health service which was focused principally on the patient. Carers felt comforted and reassured by the simple thought that the nurse on the other end of the phone knew their name. Consequently they felt supported, comfortable and more confident in telephoning the service if the need arose. This study therefore adds to the evidence base for the value of out-of-hours services, with users' and patients' voices coming through to support the value of a service which

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offers individualised and tailored care and support at this most difficult time.

Recommendations:

When designing or providing services which will support patients who wish to die at home, consideration should be given to:

- The use of a proactive telephone service model (as opposed to providing a reactive service) is strongly advocated
- Particular attention should be given to the provision of support during night time when patients and carers feel particularly vulnerable
- The inclusion of carers/family members in the support provided. 

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