Better care at any hour for palliative patients

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Accessing out of hours care is still a challenge for UK palliative care patients, even several years after the introduction of phone help line services like NHS24 and NHS Direct. Scottish researchers have specific recommendations for a more detailed and regular communication strategy to improve patients' care, which are published by SAGE in the journal *Palliative Medicine*.

Palliative care patients can expect help from familiar primary care team professionals around a third of the time - but when unexpected events occur out of hours (OOH), an unfamiliar team often steps in, and the patient may be sent to hospital inappropriately, or against their wishes.

Most patients state they would prefer to die at home. Only about a quarter of patients actually achieve this in the UK, with about half dying in hospital and the remainder passing away in nursing or care homes or outside the health service.

Major changes to OOH primary care took effect in the UK during 2003-2004, leading to particular concerns on palliative care patients' behalf. General practitioners (GPs) are no longer responsible for OOH care of their patients, who now call a central number to speak to a nurse in a call centre, a service known as NHS24 in Scotland, and NHS Direct in England and Wales. Even before these changes, GPs and other health professionals were concerned about continuity of care, access inequalities and variable care quality for this vulnerable patient group.

Dr Cameron Fergus, a palliative medicine consultant at Borders General

Hospital, Melrose, Scotland together with colleagues Dr David Chinn and Professor Scott Murray from the University of Edinburgh conducted interviews and gathered census and National Health Service (NHS) statistics on palliative care in the Levenmouth area, on the east coast of Scotland. The researchers also directly observed NHS24, community and specialist palliative care services to assess the current challenges and develop recommendations.

The community of Levenmouth is relatively deprived, and has both a high elderly population and an increased level of long-term life-limiting illness. Patients here might be expected to use OOH services more than average. Interviews with patients, GPs, palliative care professionals, district nurses and nurses offering OOH advice via NHS24 brought a number of core themes to light. The first was a need for better communication. GPs have been encouraged to complete special notes to inform the OOH service about patients who may contact NHS24 since its introduction in Scotland. However these notes were not specific enough for palliative care patients, were often sent too late and were generally under-used. District nurses were frustrated that they had to contact NHS24 to organize patient visits but could not directly discuss the patient with the OOH GP, and the outcome of a GP visit would not be available to a second nurse needing to make another visit OOH.

Some patients and their carers were reluctant to contact NHS24, describing the process as a 'rigmarole'. Many had found using the helpline stressful and cumbersome. They were also reluctant to use OOH services, through misunderstanding of its functions or because they were unwilling to speak to a stranger. Some believed mistakenly that NHS24 could access their full health records. Many patients practiced 'self-triage,' either waiting to see their own doctor and risking harm, or calling 999 (the UK emergency number) or visiting Accident & Emergency departments with their health problems.

Some clinicians also saw a need for certain palliative patients to bypass NHS24, and allowed them to contact nurses or other medical services directly. The authors suggest that these difficulties may occur in other areas of the UK, too, although a number of local developments are addressing some of these issues.

"As palliative care evolves, the management of patients is becoming increasingly complex, and drugs are often used with which an OOH doctor may not be familiar," says Dr Fergus. If special notes from GPs are not being used for these patients, visiting OOH doctors are likely to be faced with an unfamiliar situation with no information or suggestions to help them manage the patient. "As some of these doctors may not be familiar with local services, there is a danger that those patients with the most complex needs might be admitted, and that this admission might be to an inappropriate service, or against the express wishes of the patient and family."

The study also highlights the lack of detailed statistics available about palliative care patients using OOH services and suggests that health professionals could better capture these data in future.

The authors recommend a special dedicated form (enhanced special note) for GPs to send to NHS24 with full information about palliative care patients. The form should be easy to send electronically and have a regular review date to keep it current, especially for patients on complicated drug regimens. Electronic palliative care summaries are now being developed in Scotland and will be routinely sent, with patient consent, to OOH services to improve communication.

The authors also recommend expanding patient-held nursing notes so that all visiting professionals should routinely complete them. They further recommend that certain patients with complex needs should be allowed to bypass NHS24 to access specialist services (where they exist)

OOH. Such a scheme, where palliative care patients are provided with a direct local contact number and the local service has details of their condition, has been in place for some time in the Borders Region of Scotland and the North East of England.

More information: Assessing and improving out-of-hours palliative care in a deprived community: a rapid appraisal study by CJY Fergus, DJ Chinn and SA Murray is published in Palliative Medicine published by SAGE. DOI:10.1177/0269216309356030

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