

## Survey

# Access to specialist palliative care to manage pain in people dying at home: give them a VOICE

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**Commentary on:** Elmokhallati Y, Woodhouse N, Farragher T, *et al.* Specialist palliative care support is associated with improved pain relief at home during the last 3 months of life in patients with advanced disease: analysis of 5-year data from the national survey of bereaved people (VOICES). *BMC Med* 2019. <https://doi.org/10.1186/s12916-019-1287-8>.

## Implications for practice and research

- ▶ People who receive specialist palliative care or have a stated preference to die at home have a significantly higher chance of experiencing good pain relief as they die, irrespective of their disease aetiology.
- ▶ People dying with cancer receive better pain relief than those dying of non-cancer disease.
- ▶ Access to specialist palliative care services and advance care planning should be available to all; irrespective of diagnosis.
- ▶ Researchers and policymakers should consider how to ensure improvements in pain management for patients at home through advice and support from community specialist palliative care services.

## Context

Pain is highly prevalent and debilitating in advanced progressive disease with more than half of patients reporting pain as they approach end-of-life.<sup>1</sup> UK policy supports the need for improved quality of end-of-life care for people dying at home, yet despite most people stating a preference to die at home, the majority die in hospital.<sup>2</sup> Pain relief, especially in older adults, and especially those with a non-cancer diagnosis, may be harder to obtain because of their limited access to specialist palliative care services. The study authors sought to examine the factors associated with good pain relief for those dying at home in the last 3 months of life; specifically the relationship between pain relief while dying at home and the receipt of specialist palliative care.<sup>3</sup>

## Methods

Researchers examined 5 years of data (between 2011 and 2015) from the national cross-sectional survey that seeks the Views of Informal Carers—Evaluation of Services (VOICES) that collates information about the quality of death.<sup>2</sup> A sample of 1 10763 completed surveys (a response rate of 45%) were included. Survey results are based on a relative's or friend's perspective on the quality of end-of-life care provided to the decedent.

## Findings

Almost 40% of the sample met the study's inclusion criteria (n=43 509) with people over the age of 75 years accounting for almost two thirds

of decedents. Overall only one third received specialist palliative care in the 3 months leading up to death. People with a diagnosis of cancer were more likely to be referred to specialist palliative care support at home and more likely to experience good pain relief at the end-of-life. Similarly having a recorded preference for a place of death was more likely to result in better pain relief, compared with those who had not indicated a preference.

## Commentary

The study, through secondary analysis of the VOICES data, provides a valuable insight into the experiences of pain relief associated with the receipt of specialist palliative care and the preference in dying at home. Various health and social care policies espouse drivers to ensure end-of-life care be closer to home and in patients expressing and recording their wishes and preferences for end-of-life care. Quite rightly, the authors acknowledge a difficulty in explaining the association between the involvement of specialist palliative care and in a stated preference for place of death in achieving good pain relief. Given that the majority of cases included in their sample died from a cancer related diagnosis it may be that this group of patients were more likely to have been offered and able to engage in the process of advance care planning.

The authors note some limitations to their study, most notably that the data is a post-bereavement survey that uses the perceptions of the decedents relatives as a proxy measure for the actual experiences of the patient. We know from other studies that their recollections and perspective of the dying process may be different from the actual experience; similarly conducting research on people with advanced progressive disease is complex at best. However the validity and reliability of proxies, while having its drawbacks, is still recognised as a valuable resource in end-of-life care research.<sup>4</sup>

The challenge arising from this study is for policy makers, researchers and service providers to ensure that specialist palliative care and the option to engage in advance care planning is equitably available across all life-limiting diagnoses.

**Competing interests** None declared.

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