

Unequal pain relief at home for dying patients

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Pain relief and end of life care is not being provided equally to people with advanced progressive diseases who were at home during their last three months of life, according to a study of 43,000 people who died across England.

The data for the study was drawn from responses to the National Bereavement Survey (VOICES) in England between 2011 and 2015, which asks care provided to a person who has died.

Just 10% of patients who died of a non-cancerous disease received palliative care at home, compared to 66% of cancer patients.

Led by the University of Leeds, the findings revealed that people who did access palliative care at home were 2.7 times more likely to have experienced good pain relief compared to those who did not receive palliative care.

The association between good pain relief and palliative care at home occurred regardless of the type of disease that patients had, but access to palliative care was not provided equally.

Lead author Dr. Yousuf Elmokhallalati, from the University of Leeds, said: "This research shows that palliative care is associated with significant benefits to people with every kind of progressive disease, but this is not reflected in the spread of people that are being offered palliative care.

"We need to ensure that all people, whether they have cancer, heart or lung diseases, or any other life-limiting condition, are being offered appropriate support towards the end of their lives."

Published in the journal BMC Medicine, the study is the first to suggest there are significant reductions in pain for those receiving palliative care at home. It was conducted by researchers from the St Gemma's Academic Unit of Palliative Care led

by Mike Bennett, Professor of Palliative Medicine at the University of Leeds, which works in partnership with St Gemma's Hospice in Leeds.

A British Medical Association report in 2016 showed that pain is the most important concern of both the public and of doctors when considering a patient who is facing a terminal illness.

families or close relatives to reflect on the quality of The new study also suggests that patients who had planned where they wanted to die are nearly twice as likely to experience good pain relief compared to those who had not, showing the value of planning ahead and co-ordinating the support of healthcare professionals.

> Only a quarter of patients were found to have recorded a preferred place of death, and cancer patients were nearly three times more likely to have a preference recorded compared to non-cancer patients (36.6% of cancer patients vs. 13.1% of noncancer patients).

Funded by the National Institute for Health Research (NIHR), it also found that the pain relief experienced by patients accessing palliative care in the home was approaching the levels experienced by those receiving care in a hospice.

Within the full VOICES survey, 87% of patients who died in a hospice experienced good pain relief, compared with 66% of those who received palliative care support in their home, and 37.5% of those who did not receive support in their home.

Previous research by the same group in 2018 revealed inequalities in the duration of palliative care being provided to patients across England, with cancer patients referred for care around 53 days prior to death, compared with around 27 days prior for non-cancer patients.

Professor Bennett said: "It's already been established that the home is the place where pain



is least well controlled, so our findings clearly illustrate the importance of access to <u>end of life</u> <u>care</u>.

"These results, combined with our previous research, suggest that pain relief and access to palliative care is particularly poor for older patients, those with non-cancer diseases and those who live in the North of England. These inequalities must be challenged."

The study was observational and found an association between access to <u>palliative care</u> and <u>pain relief</u>, so it was unable to determine cause and effect.

More information: 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 Medicine* (2019). DOI: 10.1186/s12916-019-1287-8

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