Dying at home leads to more peace and less grief, but requires wider support

October 8 2015

Dying at home could be beneficial for terminally ill cancer patients and their relatives, according to research published in the open access journal *BMC Medicine*.

The study shows that, according to questionnaires completed by their relatives, those who die at home experience more peace and a similar amount of pain compared to those who die in hospital, and their relatives also experience less grief. However, this requires discussion of preferences, access to a comprehensive home care package and facilitation of family caregiving.

Previous studies have shown that most people would prefer to die at home. In the UK, US and Canada, slightly more appear to be realising this wish, while in Japan, Germany, Greece and Portugal, a trend towards institutionalised dying persists.

Despite differing trends, the most frequent location of death for cancer patients remains hospital. Evidence regarding whether dying at home is better or worse than in hospital has, however, been inconsistent.

The new study took place in four health districts in London covering 1.3 million residents. 352 bereaved relatives of cancer patients completed questionnaires after their death - 177 patients died in hospital and 175 died at home. The questionnaires included validated measures of the patient's pain and peace in the last week of life and the relative's own grief intensity.

Lead author Barbara Gomes from the Cicely Saunders Institute at King's College London, UK, said: "This is the most comprehensive population-based study to date of factors and outcomes associated with dying at home compared to hospital. We know that many patients fear being at home believing they place an awful burden on their family. However, we found that grief was actually less intense for relatives of people who died at home.

"Many people with cancer justifiably fear pain. So it is encouraging that we observed patients dying at home did not experience greater pain than those in hospitals where access to pain relieving drugs may be more plentiful. They were also reported to have experienced a more peaceful death than those dying in hospital."

The study found that over 91% of home deaths could be explained by four factors: patient's preference; relative's preference; receipt of home palliative care in the last three months of life and receipt of district/community nursing in the last their months of life. When Marie Curie nurses (which provide additional home support) were involved, the patient rarely died in hospital. The number of general practitioner home visits also increases the odds of dying at home.

Three additional factors were also identified that had been previously overlooked - length of family's awareness of that the condition could not be cured, discussion of patient's preference with family, and the days taken off work by relatives in the three months before death. The authors say this challenges current thinking about the influence of patient's functional status, social conditions, and living arrangements, which showed no association once other factors are considered.

Barbara Gomes said: "Our findings prompt policymakers and clinicians to improve access to comprehensive home care packages including specialist palliative care services and 24/7 community nursing. This is

important because, in some regions, the workforce providing essential elements of this care package is being reduced."

The researchers also highlight the crucial role of families in caring for patients at home and in decision-making processes, and the need to facilitate family caregiving.

Barbara Gomes added: "Many relatives see dedicated care as something they would naturally do for their loved one, but it still represents out-of-pocket money or days off their annual leave. Some governments, for example, in Canada, the Netherlands, Norway and Sweden, have set up social programmes or employment insurance benefits, similar to maternity leave, aimed at supporting families to provide care for their dying relatives.

"We urge consideration of similar schemes where they do not exist, with the necessary caution associated with complex public health interventions - careful development, piloting and testing, prior to implementation."

Limitations of the study include its retrospective and observational nature, showing associations which do not necessarily indicate causality. The transferability of findings to regions outside of London, where home care services are less available, is uncertain. Subjective factors, pain and peace are also vulnerable to recall and observer bias from respondents.

More information: Barbara Gomes et al. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study, *BMC Medicine* (2015). DOI: 10.1186/s12916-015-0466-5