Timing of referral for hospice-based palliative care varies nationwide

Referrals for hospice-based palliative care vary in terms of their proximity to the time of death, according to a retrospective study by the National Institute for Health Research (NIHR), summarised in an NIHR Signal. The study found that referrals occur closer to death for older people than for younger people, and for patients who do not have cancer.

This retrospective study collected data from clinical notes in 64 UK hospices. It included 42,758 adults aged over 17 years who died in 2015. Participating hospices:
- Represented a third of those located in the UK;
- Were a mix of charity-managed and NHS-managed sites;
- Varied both in geographical location and size.

The study found that people aged under 50 years of age had been referred for hospice-based palliative care about one month before people aged 75 years or over. In addition, those people with dementia or who had had a stroke had been referred to a hospice for palliative care approximately nine days before death, compared with those who had other diseases – such as motor neurone disease and cancer – who were referred much earlier.

In the UK, approximately 95% of inpatient specialist palliative care beds are located in hospices. In total, 88% of hospices are charitable organisations and 12% are NHS units. The availability of hospice care varies across the country and the patterns of referrals to end-of-life services are poorly understood. This study attempted to understand how hospices are used by collecting data on the timing of referrals. Previous service research had relied on data from hospital episode statistics, whereas this study aimed to survey UK hospices directly.

Existing evidence shows that some people who are near the end of life have a better quality of life and better symptom control if they receive specialist palliative care. Relatives of people who are deceased have reported lower satisfaction rates for hospital-based end-of-life care than relatives of those who died at home – without hospice support. In spite of this, many people in the UK still die in hospital. International guidance on referral to palliative care for people who have cancer recommends that a referral for specialist palliative care is made within eight weeks of their being diagnosed with advanced disease (Osman et al, 2018).

This research highlights the need to better understand the reasons for such variations in the timings of referrals to hospice for specialist palliative care and the need to ascertain whether there are ways in which referrals to such specialist care could be improved.

Implications for nursing

This study is the first to provide detailed data on patterns of referrals to UK hospices. It highlights variations in referral patterns depending on age, disease and location. Younger people and those with cancer were more likely to receive hospice care earlier in their illness trajectory.

Future research needs to explore the reasons behind these variations. Non-specialist staff may require additional support to recognise the signs of death sooner to enable earlier referral to specialist services if it is considered appropriate.

Box 1. What did the review find?

- The median time between referral for hospice palliative care and death was 48 days
- Approximately 40% of referrals were made within 30 days of death; for people living in Wales, referrals were made within 17 days of death (the shortest time)
- People aged 75 years or older were referred 39 days before death; this was 59 days for those aged 50-74 years and 78 days for people who were younger than 50 years of age
- People with motor neurone disease were referred, on average, 109 days before death; among people with breast cancer, the average was 81 days, and for those with dementia or those who had had a stroke, the average was nine days
- Most patients in a hospice had cancer (77%); London had the highest proportion of non-cancer patients (30.2%), while Wales and Scotland had the lowest (10.3 and 10.0%, respectively)