

Thousands are missing out on palliative care because of unfair provision

By Josie Dixon

A significant minority of people – at least a fifth of everyone who dies – are not receiving the palliative care they need. Our [study](#) on equity in palliative care, funded by Marie Curie, also found that some groups are less likely to receive this care than others.

We undertook a wide-ranging literature and evidence review, including looking at the economic evidence, and also carried out new analyses of data from the [National Survey of Bereaved People in England](#) with colleagues at the Office of National Statistics.

What is palliative care?

There is sometimes confusion about what palliative care is. It is often thought to be care for people with cancer in the last weeks and days of their life. However, palliative care is for *anyone* with serious illness experiencing pain, other distressing symptoms or emotional or psychological distress, and it can be provided at any stage of illness

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Effective palliative care is active and holistic, with the [World Health Organisation](#) (WHO) emphasizing the importance of ‘early identification and impeccable assessment’. And it requires good coordination between the professionals delivering care.

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In the UK, it is delivered both by specialist palliative care professionals with accredited training, usually working as part of multi-disciplinary teams, and by generalists such as GPs, district nurses, hospital doctors, ward nurses, allied health professionals, staff in care homes, social care staff, social workers, chaplains and others.

Who is not getting the palliative care they need?

The [Palliative Care Funding Review](#) in 2011 estimated that 92,000 people in England are not receiving the palliative care that they need. By implication, there are likely to be a further 6,000 people in Wales, 3,000 people in Northern Ireland and 11,000 in Scotland not receiving the care they need. This is about a fifth of everyone who dies each year. We also know from the [National Survey of Bereaved People in England](#) that a quarter of people receive end of life care that their families consider to be poor.

Our research shows that some groups are significantly less likely to receive the care they need than others:

- *People with conditions other than cancer*

Currently only 20% of referrals to specialist palliative care are for people with conditions other than cancer. This is up from 12% in 2008, which is encouraging, but is still much less than the 70% of people who die from non-cancer conditions each year. People undergoing active cancer treatment and with hematological cancer are also less likely to get a specialist referral.

But what is also concerning is that, during their last three months of life, people with conditions other than cancer also receive less care from *generalists*, such as GPs and community nurses.

- *People aged 85 or over*

People aged 85 or over also receive little specialist palliative care: they account for 39% of deaths but just 16% of specialist referrals. This figure is up from 11% in 2012, but is still far from equitable. The needs of people in this age group are commonly under-identified by healthcare professionals, possibly because illness and death are seen as more expected in old age. It may also be that people in this age group under-report their symptoms. We also found that there may be confusion about

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the role of the geriatrician in providing palliative care.

- *Black, Asian and Minority Ethnic groups*

People from BAME groups are just as likely to be referred to specialist palliative care services as people of white ethnicity when one takes into account their age profile. They receive similar types of community-based services and are as likely as people of white ethnicity to die at home. However they report poorer quality of care, they rate care from care homes particularly poorly, and they are more likely to die in hospital than a care home.

- *People living in more deprived area*

There is no evidence that people from more deprived areas have less access to community-based services. However, they are less satisfied with the care they receive, are less likely to feel treated with dignity by all of the professionals involved in their care and they also more frequently die in hospital. There is not much data on spending on palliative care locally, but what there is suggests unclear and variable local spending decisions, unrelated to levels of need.

- *People without a spouse or partner*

People without a spouse or partner are less likely to receive home-based services, to die at home, have their pain well-controlled or receive care that their families consider to be high quality. This may be because spouses or partners can help ensure high quality care by informally coordinating the care of different professionals, by acting as advocates and by providing care directly (e.g. administering medications).

Why is this happening?

The purpose of our study was primarily to map what *is* happening; to see if there were inequities in access and outcomes, rather than to look closely at causes. However, we identified a range of service gaps that need to be addressed.

In hospitals there is limited access to face-to-face specialist palliative care for inpatients, with only 21% of hospitals providing access 7 days a week despite national recommendations that they do so, and only 2% providing round-the-clock access. There is also often limited training in end of life care for staff and evidence of poor communication with

patients about their care. Hospital end of life care is also consistently judged to be of poorer quality than that in other settings.

In the community, GPs may experience conflicting pressures on their time, and may lack confidence, knowledge and skills in end of life care. They may look to others to take more active or lead roles. Commonly, there is confusion about roles and responsibilities, poor multi-disciplinary working and poor coordination with specialist teams.

Care homes are increasingly providers of end of life care, with the number of people dying within a year of admission to a care home increasing from 47% in 2008 to 56% today. However, there can be insufficient support from external healthcare providers and care homes themselves may lack policies, guidance and capacity to deliver good end of life care.

How can we afford to make sure everyone receives the palliative care they need?

There is need for investment to extend palliative care provision to everyone who would benefit from it. Service gaps need to be addressed, including finding new and better ways of delivering generalist care and care for people with conditions other than cancer. New investment is especially needed to meet the growing demand for palliative care from an ageing population.

The evidence we looked at in our study does not shed much light on how much this would cost. However, available research evidence, mostly from evaluations of palliative care services, indicates that – once services *are* in place – patients and families not only have better outcomes (including better-managed symptoms and dying in their preferred place), but the costs of providing palliative care are offset by fewer emergency hospital admissions and fewer avoidable hospital deaths. Good quality palliative care may even provide annual net savings, with several studies suggesting that these might amount to more than £30 million in England, £2 million in Wales, £1 million in Northern Ireland and £4 million in Scotland.

Further information

The full report – Equity in the Provision of Palliative Care in the UK: Review of Evidence – is available at www.pssru.ac.uk/publication-details.php?id=4962.

Links to studies and evidence mentioned in this post are available in the report.

About the author

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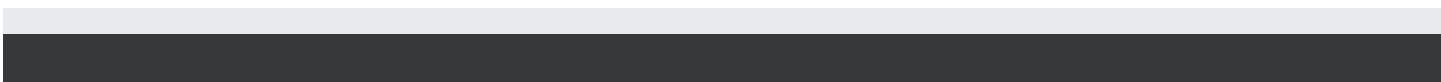
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