



¹ Cicely Saunders Institute, King's College London, London, UK

² Chesterfield Royal Hospital, Chesterfield, UK

³ Primary Care Unit, University of Cambridge, Cambridge, UK

Correspondence to: IJ Higginson: irene.higginson@kcl.ac.uk

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Dying at home during the pandemic

Increase in home deaths could be because of preference or pressure

Irene J Higginson,¹ David Brooks,² Stephen Barclay³

Data from the Office for National Statistics show that covid-19 was responsible for most of the 76 000 excess deaths during 2020 in England and Wales, with only around 2000 attributable to other causes.¹ The number of deaths from all causes in private homes increased by about one third to 167 000 in 2020, compared with an average of 125 000 between 2015 and 2019.

Around 41 000 more people died in private homes than in a normal year (which is more than half of the total number of excess deaths) but only a small number (just over 3000 or 7%) were recorded as being due to covid-19.¹ Most of these deaths at home were from underlying causes seen every year: dementias (which increased by 65%), heart and lung diseases, cancers, and neurological diseases.² Some covid-19 deaths that occurred at home may have been wrongly attributed to these conditions, especially early in the pandemic when symptoms were poorly understood and testing scarce. Nevertheless, this is still likely to represent a significant shift of people dying of causes other than covid-19 from hospital to home.

Many people prefer home over hospital for their end-of-life care,³ and, although some people do not have preferences regarding place of care,⁴ the mismatch between preferences and reality is well documented. In one survey of 138 older adults in England, Ireland, and the US, 56% of respondents said they would prefer to die at home, and one quarter specifically did not want to die in hospital. Despite this, most participants subsequently died in hospital. Only 25% achieved their first preference.⁵

Preferences are influenced by trade-offs between competing priorities, expected outcomes, levels of engagement, and abilities to form and express preferences.⁶ Was the increase in home deaths during 2020 evidence of improved achievement of peoples' preferences or the result of pandemic related displacement from healthcare facilities?

Hospitals and community services worked hard to free up beds for increasing numbers of covid-19 admissions. This may have facilitated discharge of patients at the end of life, helping some to achieve their preference for home care. Alternatively, the pandemic may have influenced peoples' preferences outside hospitals—through concerns about restricted visiting, fear of infection, and motivation to reduce pressure on stretched hospital services.

Unfortunately, we have no systematic evidence about the quality of home care given to people towards the end of life during the pandemic. Such information is vital if we are to understand whether the increase in deaths in private homes is a reflection of preference

or of poor quality alternatives because of pressured hospital services.

Care at home can be of high quality,⁷ particularly when home services are available at all times, symptoms are well controlled, and communication is timely and skilful.⁸ Rapid innovations to anticipatory prescribing by general practitioners observed during the pandemic may have aided symptom management for patients at home.⁹ However, the Marie Curie report on dying during the pandemic and other research present a mixed picture.^{10 11} For people needing palliative care during the pandemic, research is urgently need to find out how well symptoms were controlled; how families, preferences, and priorities were supported; and how easily services were accessed, including by remote consultation.

Sustaining the shift

Any shift towards more deaths at home needs to consider the size of the community palliative care workforce. In 2018, researchers predicted that as the annual numbers of deaths increased over the coming two decades, community capacity would need to double unless hospital capacity increased substantially.¹² During 2020, pressure on community palliative and end-of-life care surged, reaching levels of need not expected until 2040. Combined with existing gaps in the workforce, this suggests an urgent need to grow and train community clinicians skilled in palliative care.

Help from family members and informal carers is a critical and often overlooked component of care at home. The furlough scheme and increase in working from home may have made it easier for some people to provide the flexible care needed to support those important to them at the end of life. In research done before the pandemic, for example, support from family members significantly increased the odds (range 1.78 to 7.85) of patients with cancer dying at home.¹³ For others, however, pandemic restrictions such as shielding and travel bans may have prevented them from providing support.

A detailed plan for better palliative care, *You matter because you are you*, recently published by Cicely Saunders International, gives a comprehensive approach to filling the gaps in palliative and end-of-life care.¹⁴ Providing expertise in places where people are cared for, joining up care, empowering patients to access palliative care, and increasing community support, training, and research are all essential to ensure that patients receive high quality end-of-life care in the place of their choosing—often at home.¹⁴

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