

Choice at the end of life, wealth and other possible mediators

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In their paper examining the relationship between socioeconomic position and receipt of hospital-based care towards the end of life for older people, Davies et al.(1) demonstrate that lower wealth is associated with a higher probability of increased hospital admissions in the last two years of life and death in hospital. This is an important contribution to the literature as it adds weight to the increasing understanding of the importance of non-clinical factors such as socio-economic status to patterns and quality of healthcare and its usage. These factors have been brought into particularly sharp focus during the COVID-19 'syndemic', recognising the biological and social interactions that are important for prognosis, treatment, and health policy(2).

Place of death has long been seen as an (imperfect) proxy for care quality, with hospital deaths perceived as potentially indicating a poorer quality of death. However, place of death can and should be considered more broadly, and no one place seen as the most appropriate. Even if, for example, care at home is possible, this does not mean that death at home is preferred. Rather, there is evidence that the desire to die at home lessens with age and failing health.(3) Equally, reasons for hospital admission towards the end of life are many, yet the triggers remain largely unknown and even less understood, despite hospital remaining the place of death where a high proportion of people die in most cultures and contexts. Recent analysis of a Scottish national dataset demonstrated that social determinants including patient understanding of how to access the right care in a timely manner contributed to the extent of unscheduled care for older people in the last year of life.(4) These findings hint that the reasons behind the high levels of emergency or unscheduled hospital admissions before death are complex and multi-factorial, with important factors including public knowledge about resources and services, wealth and socio-economic position, age, and access to informal caregivers.

Older age is associated with higher rates of unscheduled care,(4) and the complexities of managing ageing and a chronic or life-limiting illness, increased dependence, and access or availability to informal caregivers(5) such as family members are likely contributing factors. Informal caregivers are integral to supporting older people to stay at home.(6) But in order to maintain dignity and social integrity, the older person may prefer to receive care by health care staff than a family caregiver.(7) Family caregivers are also impacted financially due to the impact of caregiving on paid employment, experience negative physical health due to poor self-care and negative mental health outcomes.(8) Hence, even when an older person has social and family supports, there might not be a person willing to take on a caregiving role, particularly towards the end of life, resulting in the need for in-hospital care. Even though family presence at death is considered a marker of end-of-life care quality,(9) family readiness for witnessing the person's deterioration and death should also not be assumed. A recent Australian study of in-hospital end-of-life care identified family were only present

at death in 58% of anticipated deaths.(10) Whilst the reason/s are not entirely clear, and could be partially attributed to aspects of cultural difference, such as ethnicity and religiosity, these data may demonstrate a deliberate decision by family members not to witness or be present at death, and/or an honouring of the dying person's wishes.

From a public health perspective, I commend Davies et al. on their research which provides clear justification for systems change to ensure equity in access to services to support preferred place of death, so that location of death is driven by choice, not by wealth.(1) The potential for health inequalities associated with aspects of cultural diversity such as ethnicity, language differences and religiosity and belief systems; and social factors such as health literacy and awareness of systems and services to support end-of-life care needs to be better understood. What this research highlights is a need for a whole systems approach to care, and care data. The patterns and gaps in care that people receive at the end of life need to be much more fully understood, with data from primary and community care integrated into the more commonly available hospital use data. The triggers behind care transitions must also be investigated with a focus on clinical, economic, social and cultural issues and interactions – recognising the complexity of the factors that are likely to play into choice and experience.

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