



## Demystifying Cancer Deaths—Location, Location, Location

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Death is an inevitable fact of life, however over the last few decades there has been an increasing focus on the circumstances of the event. Dame Cicely Saunders, the founder of the Hospice movement in the UK, said “How people die remains in the memories of those who live on”,<sup>1</sup> hence, an increased focus on the place of death for patients is timely. Sonal et al.<sup>2</sup> have provided an elegant study addressing the location of death of patients dying from colorectal cancer, which remains the second most common cause of cancer-related mortality in the USA, with over 52,000 deaths per year. Assessing colorectal cancer deaths in the USA between 2003 and 2019 through national databases, they have demonstrated a progressive shift of patient deaths from within medical institutions including hospitals, nursing homes, and emergency departments, to deaths at home or in a hospice. The shift, however, is not equally distributed across the population, with Black, Asian, and American Indian and Alaska Natives (AIAN) less likely to die at home or hospice compared with white decedents, and patients with lower educational status being less likely to die at home or in a hospice.

Optimal care at the end of life has been defined as being able to die free from pain, in the place of your choice, cared for with dignity and supported by the best possible care.<sup>3</sup> This is combined with an increasing desire for control and

autonomy, with the ability to say goodbye and put relationships right, with family present, and a sense of pragmatism and acceptance of the inevitable outcome. The requirement of wishes and values of the individual patient being respected is core to the approach. A ‘bad’ death is more likely to involve a prolonged death, unnecessary investigations with suffering without benefit, loss of dignity and autonomy, the absence of family, failure of acceptance of death and wishes, and values of the patient being ignored. The ‘de-medicalising’ of death has understandably been a slow evolution, with many healthcare professionals, patients and patients’ families believing it is important to continue to strive for prolongation of life at all costs. This remains a very difficult balancing act that must be tailored to each specific case and may account for some of the racial disparities identified within the study by Sonal et al.,<sup>2</sup> with discomfort around discussing death and awareness of the role of hospices<sup>4,5</sup> potentially more prevalent in certain ethnic groups. Even within individual couples, there may be a different perspective around dying at home, with different views expressed by the individual partners.<sup>6</sup> There has been development of government policies in both the USA and the UK to enable increasing access to hospice care<sup>7</sup>; however, despite this, the discrepancy of access remains, as demonstrated by the paper published in this journal.

This progressive change in location of death from hospital to home or hospice is not isolated to colorectal cancer and is reflected in other tumour types, including oesophageal cancer in the USA.<sup>8</sup> The trend is also consistent outside of cancer-related deaths, when mortality from cardiovascular disease, respiratory disease, dementia and stroke, as well as cancer, are considered.<sup>9</sup> Interestingly, again, racial and ethnic minorities were more likely to die in hospital than at home. When compared with the other causes of death, however, patients with cancer had the greatest odds of death at home or in a hospice. Sonal et al.<sup>2</sup> highlighted the fact

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that patients with lower educational status were less likely to die at home or hospice. So, could the overall disparity be accounted for by a combination of cultural themes and limitations in the awareness of the differing options in terms of places to die? There may also be a temporal element to the location, as one would perhaps expect patients with cancer to have a greater awareness of impending mortality than patients with cardiovascular disease or chronic illness and hence have greater opportunity to consider and plan the environment and circumstances for their demise. This is an important area for further research with investigation into the impact of ethnicity and culture on choice, in combination with assessment of the awareness of available options. Intervention through education could modify potentially deep-seated expectations around death and facilitate generation of new perspectives, potentially correcting the imbalance in location of death across the different ethnic groups.

The opportunity to improve the education of patients around their options with respect to the location of their demise also raises the concept of forward planning and increasing the uptake of shared decision-making and advanced care directives. Studies of elderly patients dying from colorectal or lung cancer have shown that the quality of end-of-life care from the perspective of the family is improved with earlier hospice involvement and death outside of hospital, supporting the initiation of advanced care planning.<sup>10</sup> This is a further area where educational input would be valuable to dispel the incorrect concept that utilization of advanced care planning will unduly shorten life or be more psychologically damaging to the patient and the family. The recent introduction of voluntary assisted dying in several countries may also add a further dimension to the discussion, particularly in patients with terminal cancer,<sup>11</sup> although this remains a controversial area that generates strong opinions and emotions across patients, families and clinicians alike. Financial implications are also important to consider if there is to be further transition from hospital to home or hospice deaths. For colorectal cancer, it appears that this transition actually reduces costs in Canada, and potentially in the USA, with respect to Medicare costs,<sup>12</sup> however this would necessitate redistribution of resources external to hospital facilities.

Societal expectations of dying are evolving, although discussions around the terminal phase of life remain a taboo subject across some cultures and ethnic groups. Location is an important consideration in generating the optimal circumstance for dying patients and their families, and the progressive shift to home or hospice and away from hospitals is reflective of societal changes but also mirrors disparities present within society. The ability to plan for this situation, which is probably easier in patients dying from cancer, utilizing interventions such as advanced care plans, may smooth the journey; this could provide the opportunity

for educational interventions, which could help reduce the differences across groups. This remains an area in need of further research and would benefit from consideration by both government bodies and funding bodies. Medical facilitation of patient wishes is essential and may help shift the paradigm from a depressing perspective of death to perhaps more of a celebration of life, with dying becoming, to quote Peter Pan, "... an awfully big adventure".<sup>13</sup>

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## REFERENCES

1. Saunders C. *Watch with Me: inspiration for a life in hospice care*. Mortal Press; 2003.
2. Sonal S, Jain B, Baja S, et al. Trends and determinants of location of death due to colorectal cancer in the United States. *Ann Surg Oncol*. 2023. <https://doi.org/10.1245/s10434-023-14337-y>.
3. Ellershaw JE, Lakhani M. Best care for the dying patient. *BMJ*. 2013;347:f4428. <https://doi.org/10.1136/bmj.f4428>.
4. Johnson KS, Kuchibhatla M, Tulsy JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J Am Geriatr Soc*. 2008;56(10):1953–8. <https://doi.org/10.1111/j.1532-5415.2008.01919.x>. (Epub 2008 Sep 2).
5. Johnson KS, Kuchibhatla M, Tulsy JA. Racial differences in self-reported exposure to information about hospice care. *J Palliat Med*. 2009;12(10):921–7. <https://doi.org/10.1089/jpm.2009.0066>
6. Aurén-Møkleby M, Thoresen L, Mengshoel MA, et al. 'It's not just about me': a qualitative study of couples' narratives about home death when one of the partners is dying of cancer. *Palliat Care Soc Pract*. 2023;17:1–13. <https://doi.org/10.1177/26323524231189517>. (eCollection 2023).
7. Davis FA. Medicare hospice benefit: early program experiences. *Health Care Financ Rev*. 1988;9(4):99–111.
8. Bajaj SS, Jain B, Potter AL, Dee EC, Yang C-FJ. Racial and ethnic disparities in end of-life care for patients with oesophageal cancer: death trends over time. *Lancet Reg Health Am*. 2023;17:100401. <https://doi.org/10.1016/j.lana.2022.100401>.
9. Cross SH, Warraich HJ. Changes in the place of death in the United States. *N Eng J Med*. 2019;381(24):2369–70. <https://doi.org/10.1056/NEJMc1911892>.
10. Wright AA, Keating NL, Ayanian JZ, et al. Family perspectives on aggressive cancer care near the end of life. *JAMA*. 2016;315(3):284–92. <https://doi.org/10.1001/jama.2015.18604>.
11. Phillip J, Le B, Le Brooy C, et al. Voluntary assisted dying/ euthanasia: will this have an impact on cancer care in future years? *Curr Treat Options Oncol*. 2023. <https://doi.org/10.1007/s11864-023-01126-8>.
12. Bremner KE, Yabroff R, Coughlan D, et al. Patterns of care and costs for older patients with colorectal cancer at the end of life: descriptive study of the United States and Canada. *JCO Oncol Pract*. 2019;16(1):e1–17. <https://doi.org/10.1200/JOP.19.00061>. (Epub 2019 Oct 24).
13. Barrie JM. Peter Pan. Penguin Modern Classics; 2021.

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