

Ethnicity and “aggressive” end-of-life care

Aziz Sheikh MSc MD, Sangeeta Dhami BSc MBBS

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Facilitating a good death is one of the most fundamental duties of health systems. Linked research investigated the association between ethnicity and end-of-life care in patients of Chinese and South Asian ethnicity compared with the general population of Ontario and highlights how a good death can be challenging to realize in the absence of a shared understanding of what that is.¹ In particular, in seeking to provide respectful, tailored end-of-life care in pluralist societies, it is important that essentially Eurocentric notions of what constitutes “aggressive care” are not inadvertently imposed on people who may hold different world views.²

Yarnell and colleagues carefully constructed a population-based cohort of all people who died in Ontario over an 11-year period and used this to compare provision of end-of-life care and outcomes in 3 ethnic groups, using sound methodology.¹ Key strengths included the size of the cohort, the duration and completeness of follow-up, the substantial number of events — there were almost 1 million deaths in total (almost 19 000 people of Chinese ethnicity died and more than 11 000 people of South Asian ethnicity died) — and the adjustment of findings for several potential cofounders.

The researchers found that, compared with the general population who were largely white, patients who were of Chinese and South Asian descent were more likely to be admitted to hospital, to receive intensive medical care (defined as including dialysis, mechanical ventilation, tracheostomy and cardiopulmonary resuscitation) and to be admitted to and die in intensive care unit (ICU) settings.¹ They concluded that patients of South Asian and Chinese ethnicity were “more likely to receive aggressive care,” potentially reflecting “different end-of-life preferences and communication, and the possibility of ethnicity-related disparities.”¹

Several study limitations related to categorization of ethnicity warrant consideration. First, considerable care needs to be taken not to inappropriately homogenize across broad ethnic categories such as South Asians as this may mask considerable heterogeneity in beliefs, cultures and practices within the population. However, there is often no alternative to using such broad categories, as investigators will have challenges posed by small numbers and insufficient power. We have, for example, frequently had to resort to similar approaches in the context of our studies investigating variations in health outcomes across ethnic groups in Scotland and the United Kingdom.³

KEY POINTS

- Facilitating a good death, although one of the most fundamental duties of health systems, is also one of the most challenging to realize, particularly in pluralist societies.
- Although new evidence suggests that differences in end-of-life care experiences and outcomes between people of different ethnicities may result from inappropriate “aggressive care” in Chinese and South Asian populations, it is also worth considering whether care may be suboptimal for those in the European-origin general population.
- Longitudinal, multiperspective qualitative approaches can provide clearer insights into the end-of-life expectations and experiences of patients, caregivers and health care providers, and how these evolve over time.

Second, the use of name recognition software has suboptimal specificity and, in particular, sensitivity.⁴ More fundamentally, the software assigns ethnicities to people instead of allowing them to choose for themselves. Self-assignment is preferable in the context of socially constructed, fluid variables such as ethnicity. This is because individuals may see themselves as belonging to one ethnic group in some contexts and another ethnic group in other contexts.

Third, Yarnell and colleagues did not investigate the effect of faith identity, which is likely to have a bearing on end-of-life care decisions for many patients.⁵

Notwithstanding these limitations, the linked study provides valuable insights. The findings give rise to several hypotheses that may explain the differences uncovered, a number of which the authors consider. Additional possible explanations include differences in decision-making processes between more individual- and collective-orientated cultures, and the likelihood that more of the general population may be dying in long-term care settings where care provision is less likely to be escalated than in patients being cared for at home or in hospital settings. Less awareness or acceptability of advanced care planning in Chinese and South Asian cultures is another possibility.

Yarnell and colleagues described more intensive medical care before death as aggressive care — an expression suggesting that care for the populations in question was excessive in some way.

However, it is not clear that this was the case. Our research, based on a longitudinal study of the entire population of Scotland, found that people of South Asian origin were, when age was accounted for, more likely to receive hospital care for conditions such as asthma, cardiovascular disease, diabetes and lower respiratory tract infections. However, when compared with the Scottish general population, people of South Asian origin had greater life expectancy.⁶ Such a survival advantage could be due to the healthy migrant effect or salmon bias hypothesis, but the higher rates of admission to hospital render such explanations unlikely. This then raises the question of whether more clinically appropriate, hospital-based, medical care in those of South Asian origin accounts for differences in survival. Similar survival advantages have been described in other ethnic populations in North America and Canada.^{7,8}

Therefore, a more plausible interpretation of the differences reported by Yarnell and colleagues may be that the general population in Ontario is less likely to receive “appropriate care” than people of Chinese or South Asian descent. A related limitation to Yarnell and colleagues’ research is the lack of any accompanying qualitative inquiry, which constitutes a missed opportunity to explore perspectives on care preferences, judgments on the appropriateness of care or whether patients and their loved ones felt respected in their final days.⁹ Longitudinal, multiperspective qualitative approaches can help to deliver clearer

insights into the end-of-life expectations and experiences of patients, caregivers and health care providers, and how these evolve over time.¹⁰

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Affiliations: Usher Institute (Sheikh), The University of Edinburgh; General practice locum (Dhami), Edinburgh, UK

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Correspondence to: Aziz Sheikh, aziz.sheikh@ed.ac.uk