

Few countries offer a good place to die, researchers say

January 18 2022



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Among the most troubling scenes from the COVID-19 era are the images of patients dying in isolation, unable to be with loved ones during their final moments. But even before the pandemic, harrowing deaths



were all too common in most parts of the world, a new survey of end-oflife care shows.

The study, detailed in three papers to be published in the *Journal of Pain and Symptom Management*, ranked 81 countries on how well their health systems provide for the physical and mental wellbeing of patients at the end of life. Only six countries earned grades of A, while 36 earned Ds or Fs.

The <u>survey results</u> appeared in the *Journal of Pain and Symptom Management* last month, and additional details may be found on a website created by the Lien Centre for Palliative Care, part of the Duke-NUS Medical School in Singapore.

"Society should also be judged on how well people die," says Eric Finkelstein, a palliative care expert and professor with Duke-NUS and the Duke Global Health Institute in Durham, North Carolina, who led the study. "Many individuals in both the developed and developing world die very badly—not at their place of choice, without dignity, or compassion, with a limited understanding about their illness, after spending down much of their savings, and often with regret about their course of treatment. These things are very common."

To compile the rankings, Finkelstein and colleagues surveyed more than 1,200 caregivers from several countries to identify what is most important to patients at the end of life. They then asked 181 palliative care experts across the globe to grade their countries' health systems on 13 weighted factors that people most often listed, including proper management of pain and comfort, having a clean and safe space, being treated kindly, and treatments that address quality of life, rather than merely extending life.

The United Kingdom earned the highest ranking in the study, followed



by Ireland, Taiwan, Australia, South Korea and Costa Rica, which all earned A grades. The United States earned a C, ranking 43rd of the 81 countries.

At the bottom of the rankings were 20 countries earning failing grades, many of which are low- or <u>middle-income countries</u> with fewer health resources than the top-rated countries.

"Perhaps the main conclusion from this important exercise is that most people in the world die badly—many through no treatment at all and many through excessive often futile treatment that increases suffering," says Richard Smith, a palliative care expert and former editor of the *British Medical Journal*. He and Finkelstein also serve on the Lancet Commission on the Value of Death, a global panel of palliative care experts who are expected to issue recommendations for improving end-of-life care later this year.

It's no coincidence that most of the survey's top scorers are wealthy countries with well-funded health systems, while low- and middle-income countries fared worse, says Stephen Connor, executive director of the Worldwide Hospice Palliative Care Alliance and one of the study's co-authors. "The overwhelming need for palliative care is in low and middle-income countries, where less than a third of services exist," he notes.

But Connor and Finkelstein both point to the U.S.' middling ranking as proof that money doesn't always guarantee attention to end-of-life care. In the U.S., he says, resources are often invested in last-ditch efforts to extend life, rather than measures to ensure comfort and quality of life in a patient's final days.

"We spend so much money trying to get people to live longer, but we don't spend enough money in helping people die better," says



Finkelstein, who is also the director of the Lien Centre for Palliative Care at Duke-NUS. The research was funded by the Lien Foundation, a Singapore-based nonprofit focused on improving quality of life.

The harrowing stories of COVID-19 deaths, when health care workers were often the only people allowed to comfort the dying, should bring renewed focus on end-of-life care, Finkelstein says.

"Generally, people don't talk about death. COVID has made it less taboo. We have an opportunity to continue this discussion and not just help COVID patients, but to help everyone have a better end-of-life experience," he said.

Finkelstein and colleagues hope the country rankings spur action from policymakers to improve conditions for dying patients, such as loosening restrictions on pain medications given to comfort those at the end of life.

But people don't necessarily need to wait for policy change to take steps to ensure a better end-of-life experience, Finkelstein says. He advises people of any age or health condition to make an end of life plan and discuss it with family and friends.

"Do an advanced care plan or at least express your wishes to friends and family," he says. "Don't wait. By the time you fall ill, it may be too late and folks may not know what you want."

More information: Eric A. Finkelstein et al, Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021, *Journal of Pain and Symptom Management* (2021). DOI: 10.1016/j.jpainsymman.2021.12.015



Provided by Duke University

Citation: Few countries offer a good place to die, researchers say (2022, January 18) retrieved 1 May 2024 from https://medicalxpress.com/news/2022-01-countries-good-die.html

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