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Invited Commentary | **Geriatrics**

Persisting Where Quality of Life Is Worse Than Death

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How long is too long to live in a severely impaired state? That is the question at the heart of the study by Hakimjavadi et al[1] After obtaining input from multiple stakeholders, they identified 4 states of significant impairment and studied survival of Ontario nursing home residents who developed these conditions. At admission, only a few residents were (1) totally dependent upon others (2.8%), had (2) severe communication deficits (1.8%), or (3) severe cognitive impairment defined as inability to make decisions (8.7%); however, 22.7% were (4) incontinent of urine or stool. Not surprisingly, the numbers increased over time, and developing these conditions was associated with shorter survival compared with the median of 2.5 years. However, substantial numbers of residents developing these impairments after admission survived for more than one year: 21.2%, 39.0%, 42.3%, and 48.4% for those totally dependent, unable to communicate, severely cognitively impaired, and incontinent, respectively. The focus on survival in these impaired states as outcomes is what makes this study's[1] approach unconventional—survival in states that are often regarded worse than death by patients, family, and professionals.

Research on which states would be worse than death is not new: important studies date back to the 1980s and 1990s. Scenarios presented to study participants referred to, for example, terminal illness, nursing home residence, and dementia from the perspective of patients themselves[2] and physicians.[3]

The dilemma is when and how to intervene in a state that many would consider to be worse than death. Acting on behalf of the patient, for example in advanced dementia, is often difficult for surrogates who feel that they are dictating treatment rather than respecting the patient's wishes.[2] Studies have consistently shown substantial discordance between what surrogates think patients would want and what the patients would actually want.[4] The literature also shows consistent underestimation of quality of life compared with the patient's perception, which may shift over time, accepting states of incapacity that they had perceived as unacceptable. However, Fried and colleagues[5] found that high percentages of seriously ill patients would not even choose low burden treatments if the expected outcome were severe functional or cognitive impairment. That is, almost all would have chosen low-burden treatments with good outcomes, while over 70% of them would not have wanted even low-burden treatment or were undecided if the expected outcome were severe functional or cognitive impairment.

In the Netherlands, elderly care physicians often consider it ethically problematic in people with severe dementia to attempt to cure intercurrent disease, such as pneumonia, which implies keeping the individual alive for ongoing suffering and decline.[6] Advance care planning practice in Dutch nursing homes offers a symptomatic goal of care that in fact comprises 2 underlying—potentially competing—goals: comfort plus to not prolong life. People may want to avoid anticipated longstanding suffering due to dementia, in which case physicians generally regard withholding life-prolonging treatment acceptable, while fulfilling an advance euthanasia request for a time when a patient is severely impaired or admitted to a nursing home has been, and still is, under debate.

The 4 states selected in the study from Hakimjavadi et al[1] emphasize incapacities—being unable to carry out self-care, to communicate, to decide, and to maintain continence; this is a capacity-based view of personhood. Underlying, however, are valuing autonomy and connection, and more implicitly, dignity, which we infer from the inclusion of inability to perform toileting as part of self-care and incontinence as among the 2 functional impairment outcomes studied. However, the study does not examine conditions perceived as important and perhaps even more important by patients, of which most prominently are conditions directly related to emotional suffering. These include, for example, emotional well-being, being a burden to others, manner of death, and adaptation to illness.[2] The latter was important also in a longitudinal study on mechanisms that foster dignity from the perspective of nursing home residents: how they adapt, cope, and also how others interact or view the resident in that being among disabled others made residents feel less prone to exposures of disrespect from the outer world.[7]

Therefore, an important limitation of the study by Hakimjavadi et al[1] is that states worse than death were determined by proxies, such as patient partners, professionals, and researchers from Ontario. It didn't appear that residents themselves participated in selecting states worse than death. The process of involvement also lacked transparency in weighing of perspectives and how consensus was achieved. Moreover, the impaired states were obtained from Resident Assessment Instrument Minimum Data Set assessments, which are based on measurable items reported by professionals. Therefore, states worse than death as an outcome of survival analyses would benefit from refinement, transparent reporting, and inclusion of patient views, for example through asking nursing home residents in Ontario themselves. To increase generalizability, preferably similar analyses would be conducted cross-nationally, including in more distant cultures where states worse than death may be perceived differently. A greater variety of states based on what patients find important could be examined, but researchers could also vary duration of survival. Rather than choosing 1 year, duration itself was a relevant factor in one of the early studies (in physicians in Ontario) on states worse than death without improvement.[3] That study also examined the concept of maximal endurable time.

Limitations aside, persistence in states of severe disability occurs in a substantial minority of Ontario nursing home residents and almost certainly elsewhere. In focusing on this, rather than presenting mortality predictors, the authors have adopted a person-centered approach to population-level data. The dilemma is how to intervene, which is a multifaceted problem relating to problems with surrogate decision-making, communication of prognosis, and evaluating quality of life. Large majorities of the people who developed severe impairments in this study were living with dementia. Physicians commonly find that surrogates have not considered whether prolonging survival is a meaningful goal in people with advanced dementia. In advance care planning discussions, clear understandings of prognosis and the course of dementia are crucial issues if the hope is to avoid, if possible, states that the patient would find worse than death.

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