

Publication

Advancing Long-Term Care Science Through Using Common Data Elements: Candidate Measures for Care Outcomes of Personhood, Well-Being, and Quality of Life

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To support the development of internationally comparable common data elements (CDEs) that can be used to measure essential aspects of long-term care (LTC) across low-, middle-, and high-income countries, a group of researchers in medicine, nursing, behavioral, and social sciences from 21 different countries have joined forces and launched the Worldwide Elements to Harmonize Research in LTC Living Environments (WE-THRIVE) initiative. This initiative aims to develop a common data infrastructure for international use across the domains of organizational context, workforce and staffing, person-centered care, and care outcomes, as these are critical to LTC quality, experiences, and outcomes. This article reports measurement recommendations for the care outcomes domain, focusing on previously prioritized care outcomes concepts of well-being, quality of life (QoL), and personhood for residents in LTC. Through literature review and expert ranking, we recommend nine measures of well-being, QoL, and personhood, as a basis for developing CDEs for long-term care outcomes across countries. Data in LTC have often included deficit-oriented measures; while important, reductions do not necessarily mean that residents are concurrently experiencing well-being. Enhancing measurement efforts with the inclusion of these positive LTC outcomes across countries would facilitate international LTC research and align with global shifts toward healthy aging and person-centered LTC models.

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