


Advancing International Research on Long-Term Care: Using Adaptive Leadership to Build Consensus on International Measurement Priorities and Common Data Elements

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Abstract

International research on long-term care (LTC) can valuably inform LTC policy and practice, but limited transnational collection of data on key LTC issues restricts the contributions of international LTC research. This special collection of *Gerontology and Geriatric Medicine* helps close the gap between the status quo and the potential for international LTC research by cultivating a transnational common ground of internationally prioritized measurement concepts and sowing the seeds of international LTC common data elements. The articles in this special collection address both adaptive and technical challenges to international LTC measurement, build on and complement existing LTC measurement systems, and provide diverse international perspectives on the measurement of LTC across four overarching domains: *LTC contexts, workforce and staffing, person-centered care, and care outcomes*. From large transnational teams of scholars specifying the meanings of central LTC concepts, to smaller subnational research teams testing new measures of person-centered care across diverse local LTC settings, contributors spark new insights and point in new directions for a LTC measurement infrastructure supportive of person-centered care and lifelong thriving.

Keywords

long-term care, measurement, common data element, comparative research

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International research on long-term care (LTC) provides valuable insights on a wide range of issues, including government policies (Österle, 2017); quality assurance and oversight (Carinci et al., 2015; Rodrigues, Trigg, Schmidt, & Leichsenring, 2014); infrastructure development and planning (Deusdad, Pace, & Anttonen, 2016); LTC operating models (Tolson et al., 2013); LTC staffing, workforce, and employment issues (Banerjee et al., 2012; Barken & Armstrong, 2018); care practices (Van den Block et al., 2016); and LTC quality and outcomes (Beaupre et al., 2018; Mor, Leone, & Maresso, 2014). International LTC research is growing in import due to a combination of international trends—population aging, lengthening life expectancies, increasing long-term multi-morbidity and disability, and weakening informal care networks—that have heightened the need for LTC worldwide and thus for research to inform LTC infrastructure development, delivery, policy and financing, including in low- and middle-income countries (LMICs) where the need for LTC emerged more recently (Beard et al., 2016; Hay et al., 2017; Scheil-Adlung, 2015). The *Global Strategy and Action Plan on Ageing and Health*

addresses the increasing worldwide need for LTC with the international decree that “Every country should have a sustainable and equitable system of long-term care” (World Health Organization [WHO], 2016).

LTC research based on multicountry data can valuably inform international development, policy and practice, and more broadly help prepare for ongoing population aging (National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services and WHO, 2011), but foundational knowledge and measurement gaps—including “an absence of consensus about how to define, measure, and analyse key concepts” (Beard et al., 2016)—limit international LTC research. These knowledge and measurement gaps include international differences in the

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meaning of foundational terms and concepts, like “nursing home” (Sanford et al., 2015), and in the use of comparable multi-country data (Beard et al., 2016). International LTC research that includes LMICs would be supported by many of the features that WHO (2009) has called for in describing the need for multi-country data to support health systems strengthening more broadly (i.e., not restricted to LTC), including, “a common data architecture . . . enhanced data sharing; and increased level and efficiency of health information investments.”

This special collection of *Gerontology and Geriatric Medicine* advances the development of an international LTC measurement framework consisting of a common set of data elements across countries, *Worldwide Elements to Harmonize Research in Long-Term Care Living Environments* (WE-THRIVE). The development of WE-THRIVE has been advanced by an international collaborative of LTC researchers to bridge gaps in the definition and measurement of key LTC concepts and to strengthen the potential for cross-national research using common data elements (CDEs). WE-THRIVE builds on and complements existing measurement frameworks, converging with them in some ways, such as in the shared focus on care contexts and staffing, and diverging from them in others, such as in WE-THRIVE’s prioritization of international applicability and meaningfulness and emphasis of measuring person-centered care and outcomes oriented toward healthy aging (Corazzini et al., 2019).

Using Adaptive Leadership to Build Consensus on International LTC Measurement Priorities and CDEs

This collection of *Gerontology and Geriatric Medicine* examines multiple dimensions of LTC measurement and provides valuable information to guide the development of an international LTC measurement infrastructure based on a core set of multi-country CDEs. The articles in this collection follow from several years of collaborative work, with international LTC researchers building consensus on international LTC measurement priorities and defining key measurement concepts (Corazzini et al., 2019). These efforts dovetail with the tradition of international consensus-building on a wide range of LTC issues, including international efforts to establish consensus on outcome measures for palliative and end-of-life care (Evans et al., 2013), on specific forms of physical frailty (Morley et al., 2013), and on the definition of “nursing home” (Sanford et al., 2015).

A distinguishing feature of the consortium’s effort is its attention to both technical and adaptive challenges in developing a measurement infrastructure. Technical challenges are readily identified and described challenges, with known solutions; effectively addressing them requires matching the correct solution with the

problem. By contrast, adaptive challenges are problems that are less clearly defined, do not have known solutions, and creating a solution often requires reframing perspectives or assumptions.

Most problems have a mix of technical and adaptive challenges. For example, supporting CDEs for cross-national, comparative research requires open dissemination of measurement recommendations, tools, and protocols. A technical challenge is to create an open-access electronic repository that adheres to internationally accepted standards of system architecture and metadata. Addressing this challenge requires matching the relevant informatics expertise to the development of the platform. However, there are inherently adaptive challenges related to the repository’s architecture to ensure a digitally inclusive community in line with the goal of bridging researchers based across culturally and economically diverse countries. Overlooking or ignoring the adaptive work required to address the interwoven adaptive challenges ultimately thwarts successful problem resolution. This collection reflects the WE-THRIVE’s effort to address not only the technical work that needs to be done to address the technical challenges of developing and supporting such a measurement infrastructure, but also calls out the inherently adaptive challenges and resultant adaptive work.

Articles examine internationally prioritized LTC measurement concepts in four overarching domains—*context, including policies, regulations, financing; workforce and staffing; person-centered care; and care outcomes*—and advance the identification of CDEs for international LTC research. Although the full collection of articles is more comprehensive, highlights of both technical work and adaptive work from several contributions are noted below.

Context

Diverse international contexts of LTC and cultural differences require that international LTC measurement proceed with the technical work of developing valid and reliable measures and the adaptive work of understanding and honoring local diverse values when designing a measurement infrastructure. Based on a series of in-depth discussions with LTC experts from several countries with different cultural and economic features—including China and Hong Kong, England, Sweden, Thailand, Trinidad and Tobago, and the United States—Siegal and colleagues (2019) identify a wide variety of LTC settings, propose a working international definition of residential LTC that accounts for their differences, and delineate a diverse array of services, funding, ownership, and regulations across countries and across residential LTC settings within countries. This work helps clarify both which elements of LTC contexts are relevant to measure and how to go about measuring them in LTC settings internationally.

Workforce and Staffing

Within the workforce and staffing domain, Zúñiga and colleagues (2019) reviewed the literature to explore the concepts of retention and turnover among LTC staff from an international perspective. The review identified a variety of methods to measure turnover and retention at the level of the LTC organization/facility, and at the level of the individual employee identified measures of intent to leave the job or stay in the job. In alignment with the WE-THRIVE focus on measuring strengths rather than deficits and on parsimonious, ecologically viable measurement (Corazzini et al., 2019), recommendations made for international CDEs to measure turnover and retention include a single-item assessment of individual staff intent to stay.

Person-Centered Care

Across diverse LTC contexts internationally, person-centered care is widely touted as the gold standard (WHO, 2015). However, the measurement of person-centeredness and person-centered outcomes is limited across countries, and across residential LTC settings within countries, even in countries with robust LTC measurement infrastructures, like the United States (Wilberforce et al., 2016). Addressing the gap in cross-setting measurement of person-centered care, Diana White and colleagues have advanced technical work in measure validation for determining the level of congruence between what LTC residents experience and what they consider important (White et al., in press). Such deep validation work is essential to advancing the identification of CDEs for international use.

Because the prevalence of dementia and its associated costs are growing internationally in conjunction with global population aging (WHO, 2017) and the majority of residential LTC users in many (Western) countries have progressive dementia or cognitive impairment that increasingly impedes functional capacity and heightens the need for LTC, the delivery of person-centered and person-directed dementia care is of particular concern for many LTC policymakers, practitioners, and researchers, yet both understanding and assessment of person-centered and person-directed care remains limited. This collection helps clarify the meanings of person-centered and person-directed dementia care and point to opportunities for international measurement of these complex concepts. Eleanor McConnell and Julianne Meyers disentangle several of the knotty tensions between the concepts and the assessment of person-centered dementia care, including tensions between (a) metrics versus meaning, (b) health versus social care outcomes, (c) quality of life versus quality of care versus quality of management/leadership, (d) person-centered versus relationship-centered, (e) quality monitoring versus quality improvement, and (f) collective outcome tools versus personal outcomes (McConnell

& Meyers, in press). In addition to this critical examination of person-centered dementia care and the alignment of its meaning with its measurement, Jing Wang and colleagues conducted a structured multinational and multilingual literature review to examine the concepts of person-centered dementia care and person-directed LTC in China, in both Chinese and English (Wang et al., 2019). Methodologically elegant, the article also further exhibits how increasingly commonplace terms, like person-centered care, may differ widely in meaning across contexts, highlighting one of the challenges of international LTC measurement.

Care Outcomes

Outcomes measurement and research in LTC is widely varied internationally, with some countries conducting little if any measurement and producing very limited measurement-based research, and other countries requiring extensive data collection in LTC settings and producing abundant measurement-based research (Tolson et al., 2013). Furthermore, much LTC outcomes measurement is focused on deficits or negative outcomes (e.g., functional decline, malnutrition, anxiety, depression, consumption of pharmacological agents), but a paradigm shift in LTC policy, culture, and measurement is increasingly bringing attention to healthy aging outcomes (Björk et al., 2017). Addressing the unevenness of care outcomes measurement across LTC settings internationally and advancing the focus on the potential for positive outcomes associated with healthy aging, Edvardsson and colleagues (2019) conduct a literature review of instruments to measure well-being, personhood, and quality-of-life outcomes, and conduct score-ranking of measurement instruments by international LTC researchers. The resulting recommendations for positive outcome measures to collect internationally provide a fertile ground for testing and growing LTC measurement supportive of healthy aging goals of global public health (WHO, 2015, 2016).

Implications

While the need for LTC is growing internationally, including in LMICs (Feng, 2019), and LTC policy and practice can be valuably informed by comparative international research (Doty, Nadash, & Racco, 2015; Nadash, Doty, & von Schwanenflügel, 2017), measurement of LTC is very uneven which limits the capacity of researchers to make meaningful comparisons across diverse LTC settings. Furthermore, much LTC measurement focuses on deficits and loss, but a global shift to focus on healthy aging outcomes is widely encouraged (WHO, 2015, 2016). CDEs that can be used to internationally measure key LTC concepts that are aligned with healthy aging outcomes hold promise for enhancing the capacity of research to inform the development and improvement of LTC around the world.

Diverse multidisciplinary teams of LTC researchers have advanced both technical and adaptive work to reach consensus on key LTC concepts to measure internationally and to determine how best to measure priority concepts. Building on these advances, additional technical work is needed to continue identifying and validating CDEs to measure priority concepts, and additional adaptive work is needed to ensure international LTC measurement efforts are respectful of diverse transnational differences, including differences in culture, policy, and economics. This special collection of *Gerontology and Geriatric Medicine* dovetails with global efforts to make LTC measurement more meaningful, and critically advances thinking about the potential, and the challenges, for conducting comparative international LTC research.

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