Towards Common Data Elements for International Research in Long-Term Care Homes: Advancing Person-Centered Care Across the Globe

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ABSTRACT

To support person-centered, residential long-term care internationally, a consortium of researchers in medicine, nursing, behavioral and social sciences from 21 geographically and economically diverse countries have launched the WE-THRIVE initiative to develop a common data infrastructure. The consortium aims to identify measurement domains that are internationally relevant, including in low and middle income countries, prioritize concepts to operationalize domains, and specify a set of data elements to measure concepts that can be used across studies for data sharing and comparisons. This article reports findings from consortium meetings at the 2016 meeting of the Gerontological Society of America and the 2017 meeting of the International Association of Gerontology and Geriatrics, to identify domains and prioritize concepts, following best practices to identify CDEs that were developed through the U.S. National Institutes of Health/National Institute of Nursing Research's common data elements (CDEs) initiative. Four domains were identified, including organizational context; workforce and staffing; person-centered care; and care outcomes. Using a nominal group process, WE-THRIVE prioritized 21 concepts. Concepts converge and diverge with existing measurement infrastructures. Conceptual convergence (e.g., concepts in the care outcomes domain of *functional level* and *harm-free care*) provides further support of the critical foundational work in LTC measurement endorsed and implemented by regulatory bodies. Conceptual divergence (e.g., concepts in the person-centered care domain of *knowing the person* and *what matters most to the person*) highlights current gaps in measurement efforts and is consistent with WE-THRIVE's

focus on supporting resilience and thriving for residents, family and staff. In alignment with the World Health Organization's call for comparative measurement work for health systems change, WE-THRIVE's work to date highlights the benefits of engaging with diverse LTC researchers, which includes those based in low and middle income countries, to accomplish a measurement infrastructure that integrates aspirations of person-centered LTC.

INTRODUCTION

Recently published position statements by the International Consortium of Professional Nursing Practice in Long-term Care Homes [1] and the International Association of Gerontology and Geriatrics Consensus Group [2] identify critical gaps in our empirical knowledge to support high-quality, person-centered residential long-term care (LTC). From a global perspective, key to accomplishing this agenda is the ability to develop international common data elements (CDEs) that facilitate LTC data sharing and aggregation, improve LTC data quality, and support common outcomes measures, among other benefits. In this article, we describe an effort that draws on the National Institutes of Health (NIH) CDE initiative [3] to identify CDEs for research in LTC homes that are relevant across countries and could be used internationally. The World Health Organization has identified such comparative measurement work as one of the most critical levers for health systems change [4, 5].

Defining characteristics of common data elements in relation to existing work

Our efforts to identify LTC CDEs for global use are grounded in a person-centered and strengths-based ethos [6] with the purpose of developing residential LTC systems that support resilience and thriving among LTC residents, families and staff. Our person-centered and strengths-based perspective contrasts with the predominant LTC measurement paradigm, which tends to emphasize frailty and deficits, often with a single-resident focus without accounting for the interactions and outcomes of staff, families, or other residents [1, 7]. Deficit-based measurement is conducted primarily for the purpose of ensuring regulatory compliance; importantly, the majority of comparative measurement infrastructures globally have emerged from this paradigm [8, 9]. This deficit-focused infrastructure has been and will continue to be instrumental in advancing patient safety and care quality. However, the underlying paradigm

limits our ability to shift to an international, person-centered LTC research infrastructure that advances and supports well-being and quality of life among older adults, their families and care workers.

To foster a shift to person-centered LTC research, we have created an international consortium of LTC researchers, the Worldwide Elements To Harmonize Research In long-term care liVing Environments (WE-THRIVE). The consortium includes researchers based in geographically and economically diverse countries, to accomplish two preliminary goals. The first goal of WE-THRIVE is to identify fundamental measurement domains and concepts of residential LTC that are important internationally, and the second goal is to establish consensus on core data elements to measures concepts within each domain. WE-THRIVE's overarching goal is to collaboratively develop an international LTC research measurement infrastructure that can be used efficiently in diverse, residential LTC settings for comparative research to advance person-centered care for resilience and thriving among residents, staff, and family members.

APPROACH TO CONSENSUS-BUILDING

WE-THRIVE's overall approach was guided by best practices in CDEs developed by the U.S. National Institute of Nursing Research-funded symptom science research centers [3]. Their approach, developed in alignment with The International Organization for Standardization (ISO) and International Electrotechnical Commission's standards for metadata registries [10], encompasses three broad activities for developing and using CDEs, including ensuring conceptual consistency, implementing group processes for identification and selection, and developing data collection and management protocols.

WE-THRIVE was initiated in November 2016; to date, we have engaged in a comprehensive, multi-step group process to identify core measurement domains of residential

LTC and corresponding concepts, which will inform the future selection of data elements, and the development of data collection and management protocols. The consortium includes researchers from 21 countries, including researchers from lower-middle, upper-middle, and high-income countries who are conducting research on diverse types of LTC care homes (World Bank, 2018). Our inclusive approach is congruent with the ISO Action Plan for Developing Countries [11], developed in alignment with the United Nations' Sustainable Development Goals [12].

Identifying International LTC Measurement Domains

Convening workshop: Generating Domains. WE-THRIVE first convened in a half-day workshop at the 69th annual meeting of the Gerontological Society of America (GSA) in November, 2016, in New Orleans, Louisiana. Participants included 27 LTC researchers from 11 countries, including Canada, China, Japan, Korea, Norway, Spain, Sweden, Switzerland, Thailand, the United Kingdom, and the United States. During the workshop, we reviewed NIH's CDEs framework, conducted breakout group discussions regarding critical domains for LTC measurement, and reached consensus across participants on four domains for LTC measurement that are salient internationally, including: (1) organizational context (external and internal to the residential care setting), (2) workforce and staffing, (3) person-centered care, and (4) care outcomes. During and following the GSA pre-conference workshop, WE-THRIVE membership expanded with more researchers who are committed to our LTC CDEs development work.

Post-workshop effort: Refining Domains, Engaging Stakeholders and Generating Concepts. Between GSA and the 21st meeting of the International Association of Gerontology and Geriatrics (IAGG) in July, 2017, WE-THRIVE members met in the four, domain-specific committees using a computer-based video-conference platform to begin identifying important

measurement concepts within each domain. Each domain committee included chairs or co-chairs who facilitated domain-specific discussions. Domain-specific discussions focused on potential concepts in each domain that were common to LTC settings across represented countries. The domain committee chairs met in monthly WE-THRIVE steering committee meetings to report updates and share challenges and ideas across subgroups. Figure 1 summarizes the developmental timeline of WE-THRIVE's work, totaling 8 steering committee meetings and 9 domain committee meetings that occurred in preparation for IAGG 2017.

Because of the group's commitment to global inclusiveness, a standing item for the steering committee and the domain committee meetings was to identify new WE-THRIVE members, especially those from low and middle-income countries (LMICs), to vet the work to date. We built an inclusive, flexible network of researchers with ongoing participation through face-to-face or distance-based technology that was not limited to researchers who could attend IAGG 2017. This approach is consistent with the ESSENCE on Health Research initiative's principle of building collaborative networks to strengthen LMIC research capacity [13]. Through this effort, WE-THRIVE membership continued to expand in size and diversity.

Second workshop: Nominal Group Process for Concepts. Building on the GSA workshop and the domain committee work, WE-THRIVE convened in a full-day pre-conference workshop—*Common Data Elements for International Research in Long-Term Care*—at IAGG in San Francisco on July 23, 2017. This workshop was open to all; participants included 55 LTC researchers from 13 countries, including 4 LMICs.

Drawing upon all previous activities related to identifying core domains and concepts, the consortium adopted a nominal group technique [14-16] to further specify a set of measurement concepts within each of the four domains. The nominal group technique is a structured group

process to prioritize ideas and build consensus using both silent, idea-generating and group discussion phases; it has been used previously by international groups for consensus-development in both research and non-research settings [17, 18]. As such, this approach is consistent with the consortium's inclusive approach to ensure all participants can contribute their perspectives in a way that does not privilege any one culture's engagement style.

We convened the workshop by reviewing WE-THRIVE goals and the steps of the nominal group process. Next, participants selected a domain group to join and domain committee chairs facilitated the domain-specific nominal group process. Nominal group facilitation was standardized in two ways. First, a nominal group process implementation manual was developed for use by the domain group chairs. Second, each domain chair was assisted by a graduate student or post-doctoral research fellow who was trained in using the manual prior to the workshop. Domain groups completed the following 6 steps: individual, silent generation of possible concepts within a domain (step 1); group turn-taking to share all ideas and eliminate any duplicates (step 2); group discussion and feedback of generated concepts (step 3); individual, confidential voting for the top 5 concepts considered the most important to measure across LTC settings internationally (step 4); tally of votes (step 5); and discussion of results (step 6). These steps were followed by a full-plenary session reporting out and discussion of the within-domain group results.

Through the nominal group process, we established consensus on a key set of concepts to be measured within each domain, and identified cross-country differences in the importance or meaning of the measurement concepts. Throughout the subgroup discussions, domain chairs ensured concepts identified by partners who were not present at IAGG were discussed, and encouraged participants to ask questions and share divergent perspectives. As an additional

strategy for inclusivity, participants were encouraged to write on boards around the room any thoughts not captured during the nominal group process, organized in accordance with MyHomeLife's [19] collaborative sensemaking themes (http://myhomelife.org.uk/wp-content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf).

RESULTS

Nominal Group Process: Domains and Concepts

Across the four LTC domains, participants prioritized 21 measurement concepts for which CDEs could efficiently support international research on critical LTC issues. Within each domain, the workshop participants prioritized five to six concepts.

Organizational context. Within the Organizational Context domain, participants (N=7) from China, Japan, Sweden, the United Kingdom and the United States generated 87 candidate concepts as relevant to the organizational context of residential long-term care in their countries. Six concepts were prioritized as most important to measure. All 6 concepts were endorsed by the full plenary (Table 1). Concepts included *social resources and support* for the organization; *regulations* that affect the organization; characteristics of *funding* of care; organizational *leadership hierarchy and role*; as well as the *interface between leadership and management*; and characteristics of a *desirable working environment*.

Workforce and staffing. Within the Workforce and Staffing domain, participants (N=8) from Brazil, Canada, Norway, the United Kingdom, and the United States generated 85 candidate concepts as relevant to workforce and staffing in residential long-term care in their countries. After clarifying and prioritizing discussions, 5 measurement concepts were prioritized as most important to measure and were endorsed by the full plenary (Table 1). Concepts

included *staff skills, attitudes, and knowledge* in relation to residents' needs; *staff collaboration and teamwork*, which was discussed as including supervisory control and feeling supported; *training and self-efficacy of staff*, including educational opportunities; *staff retention and turnover*, including staff's sense of feeling valued, wage competitiveness, and the desire to stay in the job; and *leadership and supervisory effectiveness*, including delegation and task allocation.

Person-centered care. Within the Person-Centered Care domain, participants (N=12) from Canada, China, Japan, South Korea, Thailand, the United Kingdom, and the United States generated 112 candidate concepts as relevant to person-centered care in their countries. Through the clarification and voting process, 5 measurement concepts were prioritized as the most important to measure and were endorsed by the full plenary (Table 1). Concepts included *relationship*, with consideration for relationships among all persons who are part of the residential care settings, including residents, staff, and family; *knowing the person*; identifying and addressing *what matters most to the person*; supporting *meaningful engagement*; and supporting a *positive environment*.

Care outcomes. Within the Care Outcomes domain, participants (N=11) from Hong Kong, Jamaica, Japan, Sweden, Switzerland, the United Kingdom and the United States generated 122 candidate concepts as relevant to care outcomes in residential long-term care in their countries; 5 concepts were prioritized through the discussion and voting process as most important to measure. All 5 were endorsed by the full plenary (Table 1). Concepts included *symptom management*, especially pain management; *functional level*; *well-being*; *personhood*, which was discussed as, 'letting people be people'; and *harm-free care*, including consideration of pressure ulcers and falls.

Collaborative Sensemaking Themes: Ideas for Reflection

Participants posted 71 comments on boards in the meeting room. Of these, 35 comments were similar across multiple participants, including the importance of resident pain (N=3 comments), outcomes that matter to residents (N=3 comments), relationships in residential care settings (N=4 comments), and care staff outcomes (N=7). While each of these sets of comments align with the final set of recommended concepts endorsed as most important, two additional sets of comments raised unique issues. The first set of comments pointed out the importance of recognizing and challenging our underlying assumptions about the role of families in care settings as positive and desired (N=6). For example, comments included discussion of how families may not always be desired by residents in care settings. The second set of comments (N=8) identified barriers to inclusion in the WE-THRIVE process; this was the largest set of comments. Identified barriers included the following: meeting attendance costs and time away from home institutions pose significant barriers for face-to-face LMIC-based researchers' participation; the assumption of the importance of person-centered care that is embedded in a cultural context that may be difficult to challenge; the risk that one may lack effective strategies to explore ontological assumptions in others' worldviews and therefore focus on what is relevant to one's culture alone; and the tension between making decisions to move forward as a group and the need for ongoing, iterative engagement, especially with LMIC-based researchers, over time.

IMPLICATIONS FOR PRACTICE, POLICY AND/OR RESEARCH

Advancing a parsimonious set of common data elements that could be applicable across diverse residential long-term care settings internationally, requires questioning the extent to which our current measurement paradigms embrace more global aspirations of supporting thriving among older adults, their families, and care staff. Our WE-THRIVE Consortium identified four domains with related concepts for measurement that both converge and diverge

with the predominant, deficits-based framework. Convergence highlights the critical foundational work in long-term care measurement conducted by researchers and endorsed and implemented by regulatory bodies, such as Inter*RAI*,[20], yet divergence invites us to consider key gaps needed to specify a person-centered, strengths-based measurement framework that can be meaningfully applied internationally.

The Organizational Context domain working group identified key parameters historically captured in organizational studies of residential long-term care settings, such as regulation and funding (see, for example [21]), but also prioritized components of the social context of care and the work environment. This prioritization is consistent with more recent measurement and empirical work of the context of care from non U.S.-based research teams [22].

Similarly, the Workforce and Staffing domain working group endorsed historically relevant concepts of staffing ratios or turnover in long-term care, while highlighting the extent to which staff are integrated into teams with effective leadership support and opportunities to learn. This latter emphasis also is consistent with recent findings from non U.S.-based research teams, about the direct effects of how staff are supported and developed on both staff and resident care outcomes[23].

The Person-centered Care domain working group coincided with U.S. DHHS/CMS issued regulatory changes that require documentation of resident preferences for person-centered care [24]. Our findings indicated that measuring preferences, while salient, may be of lower priority internationally than measuring the quality of the relationships among residents, family, and staff. This finding is consistent with more recent international consensus statements of the quality of relationships, or relationship-centered care, as fundamental drivers of person-centered care in residential LTC [1].

Similarly, during a time of important growth in technical capacity and administrative will to support expansion of MDS-like data registries across multiple countries [25], the Care Outcomes domain working group prioritized conceptually consistent measures of functional level and harm-free care, yet also prioritized symptom management as most important, and added well-being and personhood. These latter concepts are consistent with the European Union's framework of the PROGRESS Programme's recommendations for residential LTC measures [26]. Findings support the importance of refining how symptom experience and symptom management are meaningfully included, as well as understanding the interconnectedness of care outcomes with personhood.

Accomplishing the larger goal of WE-THRIVE requires building on these initial efforts to move from candidate concepts to well-defined concepts with measures that have been broadly vetted across diverse socio-cultural contexts and with multiple LTC stakeholders. The purpose of CDEs is not to generate a comprehensive battery of recommended measures, but rather to endorse a parsimonious subset of data elements that can be embedded within current and future LTC research data collection efforts. Engaging with more researchers based in LMIC-countries, and engaging with those in residential LTC settings, therefore, will be essential to take these next steps. Such vetting and selection will require in-depth consideration of issues of inclusion to foster transparency and deliberative dialogue of underlying assumptions within each domain, such as those limitations raised by participants in our collaborative sensemaking exercise.

Ultimately, our ability as a scientific community to support a rapidly evolving, global residential long-term care infrastructure will require new ways of engaging with our peer-researchers, especially those based in LMIC settings, and the development of a measurement infrastructure that integrates aspirational perspectives of thriving and resilience in aging. The

WE-THRIVE Consortium's work to date indicates both the potential of this approach to begin to build inclusive networks, as well as our shared capacity to leverage and enhance rather than replace existing measurement tools.

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Table 1. Domain Concepts and Prioritization Votes

Domain	Concept	Votes
Organizational Context	1. Social resources and support	21
	2. Regulation	21
	3. Funding	15
	4. Leadership hierarchy and role	10
	5. Leadership & management interface	9
	6. Desirable working environment	9
Workforce and Staffing	1. Staff skills, attitudes, and knowledge	36
	2. Staff collaboration and teamwork	17
	3. Training and self-efficacy of staff	16
	4. Staff retention and turnover	11
	5. Leadership and supervision effectiveness	9
Person-Centered Care	1. Relationship	39
	2. Knowing the person	24
	3. What matters most to the person	13
	4. Meaningful engagement	12
	5. Positive environment	9
Care Outcomes	1. Symptom management	33
	2. Functional Level	26
	3. Well-being	23
	4. Personhood	16
	5. Harm-free care	9

Figure 1. Overview of WE-THRIVE timeline to identify domains and concepts