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Towards Common Data Elements for International Research in Long-Term Care Homes:

Advancing Person-Centered Care Across the Globe

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8
9   **ABSTRACT**

10   To support person-centered, residential long-term care internationally, a consortium of

11   researchers in medicine, nursing, behavioral and social sciences from 21 geographically and

12   economically diverse countries have launched the WE-THRIVE initiative to develop a common

13   data infrastructure. The consortium aims to identify measurement domains that are

14   internationally relevant, including in low and middle income countries, prioritize concepts to

15   operationalize domains, and specify a set of data elements to measure concepts that can be used

16   across studies for data sharing and comparisons. This article reports findings from consortium

17   meetings at the 2016 meeting of the Gerontological Society of America and the 2017 meeting of

18   the International Association of Gerontology and Geriatrics, to identify domains and prioritize

19   concepts, following best practices to identify CDEs that were developed through the U.S.

20   National Institutes of Health/National Institute of Nursing Research's common data elements

21   (CDEs) initiative. Four domains were identified, including organizational context; workforce and

22   staffing; person-centered care; and care outcomes. Using a nominal group process, WE-

23   THRIVE prioritized 21 concepts. Concepts converge and diverge with existing measurement

24   infrastructures. Conceptual convergence (e.g., concepts in the care outcomes domain of

25   *functional level* and *harm-free care*) provides further support of the critical foundational work in

26   LTC measurement endorsed and implemented by regulatory bodies. Conceptual divergence (e.g.,

27   concepts in the person-centered care domain of *knowing the person* and *what matters most to the*

28   *person*) highlights current gaps in measurement efforts and is consistent with WE-THRIVE's

29   focus on supporting resilience and thriving for residents, family and staff. In alignment with the

30   World Health Organization's call for comparative measurement work for health systems change,

31   WE-THRIVE's work to date highlights the benefits of engaging with diverse LTC researchers,

32   which includes those based in low and middle income countries, to accomplish a measurement

33   infrastructure that integrates aspirations of person-centered LTC.

34   **INTRODUCTION**

35   Recently published position statements by the International Consortium of Professional

36   Nursing Practice in Long-term Care Homes [1] and the International Association of Gerontology

37   and Geriatrics Consensus Group [2] identify critical gaps in our empirical knowledge to support

38   high-quality, person-centered residential long-term care (LTC). From a global perspective, key

39   to accomplishing this agenda is the ability to develop international common data elements

40   (CDEs) that facilitate LTC data sharing and aggregation, improve LTC data quality, and support

41   common outcomes measures, among other benefits. In this article, we describe an effort that

42   draws on the National Institutes of Health (NIH) CDE initiative [3] to identify CDEs for research

43   in LTC homes that are relevant across countries and could be used internationally. The World

44   Health Organization has identified such comparative measurement work as one of the most

45   critical levers for health systems change [4, 5].

46   **Defining characteristics of common data elements in relation to existing work**

47   Our efforts to identify LTC CDEs for global use are grounded in a person-centered and

48   strengths-based ethos [6] with the purpose of developing residential LTC systems that support

49   resilience and thriving among LTC residents, families and staff. Our person-centered and

50   strengths-based perspective contrasts with the predominant LTC measurement paradigm, which

51   tends to emphasize frailty and deficits, often with a single-resident focus without accounting for

52   the interactions and outcomes of staff, families, or other residents [1, 7]. Deficit-based

53   measurement is conducted primarily for the purpose of ensuring regulatory compliance;

54   importantly, the majority of comparative measurement infrastructures globally have emerged

55   from this paradigm [8, 9]. This deficit-focused infrastructure has been and will continue to be

56   instrumental in advancing patient safety and care quality. However, the underlying paradigm

57   limits our ability to shift to an international, person-centered LTC research infrastructure that

58   advances and supports well-being and quality of life among older adults, their families and care

59   workers.

60   To foster a shift to person-centered LTC research, we have created an international

61   consortium of LTC researchers, the Worldwide Elements To Harmonize Research In long-term

62   care liVing Environments (WE-THRIVE). The consortium includes researchers based in

63   geographically and economically diverse countries, to accomplish two preliminary goals. The

64   first goal of WE-THRIVE is to identify fundamental measurement domains and concepts of

65   residential LTC that are important internationally, and the second goal is to establish consensus

66   on core data elements to measures concepts within each domain. WE-THRIVE's overarching

67   goal is to collaboratively develop an international LTC research measurement infrastructure that

68   can be used efficiently in diverse, residential LTC settings for comparative research to advance

69   person-centered care for resilience and thriving among residents, staff, and family members.

70   **APPROACH TO CONSENSUS-BUILDING**

71   WE-THRIVE's overall approach was guided by best practices in CDEs developed by the

72   U.S. National Institute of Nursing Research-funded symptom science research centers [3]. Their

73   approach, developed in alignment with The International Organization for Standardization (ISO)

74   and International Electrotechnical Commission's standards for metadata registries [10],

75   encompasses three broad activities for developing and using CDEs, including ensuring

76   conceptual consistency, implementing group processes for identification and selection, and

77   developing data collection and management protocols.

78   WE-THRIVE was initiated in November 2016; to date, we have engaged in a

79   comprehensive, multi-step group process to identify core measurement domains of residential

80   LTC and corresponding concepts, which will inform the future selection of data elements, and

81   the development of data collection and management protocols. The consortium includes

82   researchers from 21 countries, including researchers from lower-middle, upper-middle, and high-

83   income countries who are conducting research on diverse types of LTC care homes (World

84   Bank, 2018). Our inclusive approach is congruent with the ISO Action Plan for Developing

85   Countries [11], developed in alignment with the United Nations' Sustainable Development Goals

86   [12].

87   **Identifying International LTC Measurement Domains**

88   *Convening workshop: Generating Domains.* WE-THRIVE first convened in a half-day

89   workshop at the 69th annual meeting of the Gerontological Society of America (GSA) in

90   November, 2016, in New Orleans, Louisiana. Participants included 27 LTC researchers from 11

91   countries, including Canada, China, Japan, Korea, Norway, Spain, Sweden, Switzerland,

92   Thailand, the United Kingdom, and the United States. During the workshop, we reviewed NIH's

93   CDEs framework, conducted breakout group discussions regarding critical domains for LTC

94   measurement, and reached consensus across participants on four domains for LTC measurement

95   that are salient internationally, including: (1) organizational context (external and internal to the

96   residential care setting), (2) workforce and staffing, (3) person-centered care, and (4) care

97   outcomes. During and following the GSA pre-conference workshop, WE-THRIVE membership

98   expanded with more researchers who are committed to our LTC CDEs development work.

99   *Post-workshop effort: Refining Domains, Engaging Stakeholders and Generating*

100   *Concepts.* Between GSA and the 21st meeting of the International Association of Gerontology

101   and Geriatrics (IAGG) in July, 2017, WE-THRIVE members met in the four, domain-specific

102   committees using a computer-based video-conference platform to begin identifying important

103   measurement concepts within each domain. Each domain committee included chairs or co-chairs

104   who facilitated domain-specific discussions. Domain-specific discussions focused on potential

105   concepts in each domain that were common to LTC settings across represented countries. The

106   domain committee chairs met in monthly WE-THRIVE steering committee meetings to report

107   updates and share challenges and ideas across subgroups. Figure 1 summarizes the

108   developmental timeline of WE-THRIVE's work, totaling 8 steering committee meetings and 9

109   domain committee meetings that occurred in preparation for IAGG 2017.

110   Because of the group's commitment to global inclusiveness, a standing item for the

111   steering committee and the domain committee meetings was to identify new WE-THRIVE

112   members, especially those from low and middle-income countries (LMICs), to vet the work to

113   date. We built an inclusive, flexible network of researchers with ongoing participation through

114   face-to-face or distance-based technology that was not limited to researchers who could attend

115   IAGG 2017. This approach is consistent with the ESSENCE on Health Research initiative's

116   principle of building collaborative networks to strengthen LMIC research capacity [13].

117   Through this effort, WE-THRIVE membership continued to expand in size and diversity.

118   *Second workshop: Nominal Group Process for Concepts.* Building on the GSA

119   workshop and the domain committee work, WE-THRIVE convened in a full-day pre-conference

120   workshop—*Common Data Elements for International Research in Long-Term Care*—at IAGG

121   in San Francisco on July 23, 2017. This workshop was open to all; participants included 55 LTC

122   researchers from 13 countries, including 4 LMICs.

123   Drawing upon all previous activities related to identifying core domains and concepts, the

124   consortium adopted a nominal group technique [14-16] to further specify a set of measurement

125   concepts within each of the four domains. The nominal group technique is a structured group

126   process to prioritize ideas and build consensus using both silent, idea-generating and group

127   discussion phases; it has been used previously by international groups for consensus-

128   development in both research and non-research settings [17, 18]. As such, this approach is

129   consistent with the consortium's inclusive approach to ensure all participants can contribute their

130   perspectives in a way that does not privilege any one culture's engagement style.

131   We convened the workshop by reviewing WE-THRIVE goals and the steps of the

132   nominal group process. Next, participants selected a domain group to join and domain committee

133   chairs facilitated the domain-specific nominal group process. Nominal group facilitation was

134   standardized in two ways. First, a nominal group process implementation manual was developed

135   for use by the domain group chairs. Second, each domain chair was assisted by a graduate

136   student or post-doctoral research fellow who was trained in using the manual prior to the

137   workshop. Domain groups completed the following 6 steps: individual, silent generation of

138   possible concepts within a domain (step 1); group turn-taking to share all ideas and eliminate any

139   duplicates (step 2); group discussion and feedback of generated concepts (step 3); individual,

140   confidential voting for the top 5 concepts considered the most important to measure across LTC

141   settings internationally (step 4); tally of votes (step 5); and discussion of results (step 6). These

142   steps were followed by a full-plenary session reporting out and discussion of the within-domain

143   group results.

144   Through the nominal group process, we established consensus on a key set of concepts to

145   be measured within each domain, and identified cross-country differences in the importance or

146   meaning of the measurement concepts. Throughout the subgroup discussions, domain chairs

147   ensured concepts identified by partners who were not present at IAGG were discussed, and

148   encouraged participants to ask questions and share divergent perspectives. As an additional

149   strategy for inclusivity, participants were encouraged to write on boards around the room any

150   thoughts not captured during the nominal group process, organized in accordance with

151   MyHomeLife's [19] collaborative sensemaking themes (http://myhomelife.org.uk/wp-

152   content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf).

153

154   **RESULTS**

155   **Nominal Group Process: Domains and Concepts**

156   Across the four LTC domains, participants prioritized 21 measurement concepts for

157   which CDEs could efficiently support international research on critical LTC issues. Within each

158   domain, the workshop participants prioritized five to six concepts.

159   **Organizational context.** Within the Organizational Context domain, participants (N=7)

160   from China, Japan, Sweden, the United Kingdom and the United States generated 87 candidate

161   concepts as relevant to the organizational context of residential long-term care in their countries.

162   Six concepts were prioritized as most important to measure. All 6 concepts were endorsed by

163   the full plenary (Table 1). Concepts included *social resources and support* for the organization;

164   *regulations* that affect the organization; characteristics of *funding* of care; organizational

165   *leadership hierarchy and role*; as well as the *interface between leadership and management*; and

166   characteristics of a *desirable working environment*.

167   **Workforce and staffing.** Within the Workforce and Staffing domain, participants (N=8)

168   from Brazil, Canada, Norway, the United Kingdom, and the United States generated 85

169   candidate concepts as relevant to workforce and staffing in residential long-term care in their

170   countries. After clarifying and prioritizing discussions, 5 measurement concepts were prioritized

171   as most important to measure and were endorsed by the full plenary (Table 1). Concepts

172 included *staff skills, attitudes, and knowledge* in relation to residents' needs; *staff collaboration*

173 *and teamwork*, which was discussed as including supervisory control and feeling supported;

174 *training and self-efficacy of staff*, including educational opportunities; *staff retention and*

175 *turnover*, including staff's sense of feeling valued, wage competitiveness, and the desire to stay

176 in the job; and *leadership and supervisory effectiveness*, including delegation and task allocation.

177   **Person-centered care.** Within the Person-Centered Care domain, participants (N=12)

178 from Canada, China, Japan, South Korea, Thailand, the United Kingdom, and the United States

179 generated 112 candidate concepts as relevant to person-centered care in their countries. Through

180 the clarification and voting process, 5 measurement concepts were prioritized as the most

181 important to measure and were endorsed by the full plenary (Table 1). Concepts included

182 *relationship*, with consideration for relationships among all persons who are part of the

183 residential care settings, including residents, staff, and family; *knowing the person*; identifying

184 and addressing *what matters most to the person*; supporting *meaningful engagement*; and

185 supporting a *positive environment*.

186   **Care outcomes.** Within the Care Outcomes domain, participants (N=11) from Hong

187 Kong, Jamaica, Japan, Sweden, Switzerland, the United Kingdom and the United States

188 generated 122 candidate concepts as relevant to care outcomes in residential long-term care in

189 their countries; 5 concepts were prioritized through the discussion and voting process as most

190 important to measure. All 5 were endorsed by the full plenary (Table 1). Concepts included

191 *symptom management*, especially pain management; *functional level*; *well-being*; *personhood*,

192 which was discussed as, 'letting people be people'; and *harm-free care*, including consideration

193 of pressure ulcers and falls.

194 **Collaborative Sensemaking Themes: Ideas for Reflection**

195   Participants posted 71 comments on boards in the meeting room. Of these, 35 comments

196   were similar across multiple participants, including the importance of resident pain (N=3

197   comments), outcomes that matter to residents (N=3 comments), relationships in residential care

198   settings (N=4 comments), and care staff outcomes (N=7). While each of these sets of comments

199   align with the final set of recommended concepts endorsed as most important, two additional sets

200   of comments raised unique issues. The first set of comments pointed out the importance of

201   recognizing and challenging our underlying assumptions about the role of families in care

202   settings as positive and desired (N=6). For example, comments included discussion of how

203   families may not always be desired by residents in care settings. The second set of comments

204   (N=8) identified barriers to inclusion in the WE-THRIVE process; this was the largest set of

205   comments. Identified barriers included the following: meeting attendance costs and time away

206   from home institutions pose significant barriers for face-to-face LMIC-based researchers'

207   participation; the assumption of the importance of person-centered care that is embedded in a

208   cultural context that may be difficult to challenge; the risk that one may lack effective strategies

209   to explore ontological assumptions in others' worldviews and therefore focus on what is relevant

210   to one's culture alone; and the tension between making decisions to move forward as a group and

211   the need for ongoing, iterative engagement, especially with LMIC-based researchers, over time.

212   **IMPLICATIONS FOR PRACTICE, POLICY AND/OR RESEARCH**

213   Advancing a parsimonious set of common data elements that could be applicable across

214   diverse residential long-term care settings internationally, requires questioning the extent to

215   which our current measurement paradigms embrace more global aspirations of supporting

216   thriving among older adults, their families, and care staff. Our WE-THRIVE Consortium

217   identified four domains with related concepts for measurement that both converge and diverge

218   with the predominant, deficits-based framework. Convergence highlights the critical

219   foundational work in long-term care measurement conducted by researchers and endorsed and

220   implemented by regulatory bodies, such as Inter*RAI*,[20], yet divergence invites us to consider

221   key gaps needed to specify a person-centered, strengths-based measurement framework that can

222   be meaningfully applied internationally.

223   The Organizational Context domain working group identified key parameters historically

224   captured in organizational studies of residential long-term care settings, such as regulation and

225   funding (see, for example [21]), but also prioritized components of the social context of care and

226   the work environment. This prioritization is consistent with more recent measurement and

227   empirical work of the context of care from non U.S.-based research teams [22].

228   Similarly, the Workforce and Staffing domain working group endorsed historically

229   relevant concepts of staffing ratios or turnover in long-term care, while highlighting the extent to

230   which staff are integrated into teams with effective leadership support and opportunities to learn.

231   This latter emphasis also is consistent with recent findings from non U.S.-based research teams,

232   about the direct effects of how staff are supported and developed on both staff and resident care

233   outcomes[23].

234   The Person-centered Care domain working group coincided with U.S. DHHS/CMS

235   issued regulatory changes that require documentation of resident preferences for person-centered

236   care [24]. Our findings indicated that measuring preferences, while salient, may be of lower

237   priority internationally than measuring the quality of the relationships among residents, family,

238   and staff. This finding is consistent with more recent international consensus statements of the

239   quality of relationships, or relationship-centered care, as fundamental drivers of person-centered

240   care in residential LTC [1].

241   Similarly, during a time of important growth in technical capacity and administrative will

242   to support expansion of MDS-like data registries across multiple countries [25], the Care

243   Outcomes domain working group prioritized conceptually consistent measures of functional

244   level and harm-free care, yet also prioritized symptom management as most important, and

245   added well-being and personhood. These latter concepts are consistent with the European

246   Union's framework of the PROGRESS Programme's recommendations for residential LTC

247   measures [26]. Findings support the importance of refining how symptom experience and

248   symptom management are meaningfully included, as well as understanding the

249   interconnectedness of care outcomes with personhood.

250   Accomplishing the larger goal of WE-THRIVE requires building on these initial efforts

251   to move from candidate concepts to well-defined concepts with measures that have been broadly

252   vetted across diverse socio-cultural contexts and with multiple LTC stakeholders. The purpose of

253   CDEs is not to generate a comprehensive battery of recommended measures, but rather to

254   endorse a parsimonious subset of data elements that can be embedded within current and future

255   LTC research data collection efforts. Engaging with more researchers based in LMIC-countries,

256   and engaging with those in residential LTC settings, therefore, will be essential to take these next

257   steps. Such vetting and selection will require in-depth consideration of issues of inclusion to

258   foster transparency and deliberative dialogue of underlying assumptions within each domain,

259   such as those limitations raised by participants in our collaborative sensemaking exercise.

260   Ultimately, our ability as a scientific community to support a rapidly evolving, global

261   residential long-term care infrastructure will require new ways of engaging with our peer-

262   researchers, especially those based in LMIC settings, and the development of a measurement

263   infrastructure that integrates aspirational perspectives of thriving and resilience in aging. The

264 WE-THRIVE Consortium's work to date indicates both the potential of this approach to begin to

265 build inclusive networks, as well as our shared capacity to leverage and enhance rather than

266 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