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# Person-centered nursing home care in the United States, United Kingdom, and Sweden: Why building cross-comparative capacity may help us radically rethink nursing home care and the role of the RN

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We face a global crisis of care regarding our current and projected capacity to provide dignified, high-quality long-term care to frail elders and their families. Healthcare systems in both the United States (US) and across member countries of the European Union (EU) are striving to improve the quality of long-term care by improving the availability and preparation of the professional nursing and assistive personnel workforce, <sup>2–5</sup> translating evidence-based geriatric care into practice, and aligning care with person-centered care

values,<sup>7–9</sup> whereby the older adult and his or her family members are full partners in care, determining what and how care is provided. Person-centered care in nursing homes aims to shift the focus of how we make decisions about care to consider the person as a whole, rather than as a set of functional limitations, and to place his or her values and preferences first.<sup>8</sup> Advancing person-centered care has been identified as a care priority for long-term care health systems in the majority of developed countries, including the US and member countries of the EU.<sup>5,7,10</sup>

In the US, the nursing home (NH), 'culture change movement' aims to transform NHs from institutionalized, medicalized models of care to home-like, person-centered settings where residents direct their own care and residents' families are actively engaged in assessing residents' needs and planning care. <sup>11</sup> Emerging research shows the potential for culture change to advance higher care quality, <sup>11,12</sup> and an estimated 85% of US NHs are engaged in culturechange. <sup>13</sup> Unfortunately, many nursing homes have focused on environmental modifications alone, such as changing furniture to be more 'home-like', without attention to empowering residents and families <sup>14</sup> to be full collaborators in assessment and care planning processes, which form the foundation of person-centered care. Therefore, the full care quality benefits of culture change have yet to be realized.

Many EU countries, including the United Kingdom(UK) and Sweden, have made considerable progress in developing person-centered long-term care of older adults, relative to the US. 9,15,16 For example, US geriatric care historically conceptualizes care needs in relation to functional limitations and disabilities. By contrast, Sweden conceptualizes geriatric long-term care in relation to abilities, flipping the conceptual model of age-related changes and shifting the emphasis of the assessment and care planning process from disability-focused care to support of ongoing development along the life course. <sup>17</sup>Further, researchers in the UK and Sweden arguably have led our scientific advances in quantitative measurement of person-centered care environments in nursing homes, especially in relation to care outcomes. <sup>18</sup> Challenges in how to operationalize the ontological frame work, or how to consistently implement the core principles of abilities-focused care, however, have similarly limited the opportunity to realize care quality benefits. <sup>17</sup>

Obviously, there exist multiple, additional, socio-contextual factors of person-centered long-term care that differ across countries. For example, Sweden spends a greater share of its gross domestic product on long-term care expenditures compared to the UK or US.<sup>5</sup> Even more striking is the difference in mix of allocation of expenditures, whereby Sweden allocates proportionately more of its long-term care expenditures to home and community-based care options (aging-in-place), compared to the UK or US.<sup>5</sup> Allocation of relatively more or fewer resources, as well as whether resources are historically directed towards supporting an elderly individual to remain in his or her home and preserve independence, can be considered long-term care policy decisions that operationalize fundamental between-country differences in the assumption of an elderly individual's sense of agency or personhood. Ultimately, such differences may impact on between-country differences in extant engagement in person-centered care.

Despite these important differences in socio-contextual factors, the fundamental barriers to person-centered, high-quality care that relate to how nursing practice is operationalized, are surprisingly consistent across our countries. Issues of recruitment and retention of high-quality RNs in nursing and care homes persist, regardless of whether there is a significant RN shortage nationwide, as exists in the UK and US.<sup>2,5</sup> Additionally, over 90% of the actual care received by residents, occurs at the hands of non-nurse, direct care workers (DCWs), who – despite between-country differences such as whether DCWs earn a livable wage (the US ranks last) or the proportion who are migrant workers (the UK leads) – are largely unprepared and unsupported for the complexity of decision making required of them. Most importantly, they often make care decisions without effective linkages to nursing clinical expertise. Bowers et al. write of the need for 'coached collaborative' <sup>19</sup>(p.404) approaches that support nurses facilitating more effective direct care worker decision making to sustain person-centered care in US nursing homes.

Eliciting and incorporating resident and family preference sand values into how care is provided is a dynamic process between staff, resident, and family, often without clear a priori routines for what questions to ask or knowledge of how this work will be accomplished. We lack critical empirical knowledge of the necessary nursing staff behaviors and strategies to change the interpersonal dynamics to allow residents, families and direct care workers to engage<sup>20</sup> in new, person-centered, ways of planning and giving care that are shaped and informed by RN clinicalexpertise.<sup>21–23</sup> While comparing across our countries allows us to develop a rich understanding of the ways in which these divergent sociocontextual factors may affect care, it is the shared practice barriers that present the most opportunity to rethink previously held assumptions about the linkages between context, nurse staffing, and person centered care.

By bringing together nursing scientists from across diverse countries, each of whom has a distinct cultural lens through which to analyze and interpret data, we can foster systematic opportunities for new insights to emerge to address what is an interdisciplinary, intersectoral challenge of how to accomplish person-centered nursing home care and the role of the RN. New knowledge of how nursing staff can accomplish person-centered care in nursing homes within and across these socio-cultural contexts can elucidate critical practice factors that may accelerate the development of person-centered care in all of our countries. To that end, we propose the following actions to accelerate high-quality, person-centered long-term care:

- Foster opportunities to build and sustain international research teams of nursing scientists, engaging scientists at every stage of preparation, from the most senior faculty to doctoral students, leveraging opportunities for peer mentoring that emerge from differences in approaches to research training and mentoring. In an era of a widely accessible, computer-based infrastructure for real-time connectivity of global teams, nursing lags behind in systematically including our international collaborators at all stages of training and career development.
- Ensure the discipline of nursing is fully integrated into interdisciplinary frameworks guiding implementation of person-centered care in long-term

care, and that nursing scientists are full participants in key discussions establishing research priorities for long-term care of older adults and their formal and informal caregivers. McGilton et al.'s recent response to the International Association of Gerontology and Geriatrics global agenda is an example that highlights the critical nursing practice issues that would otherwise be over-looked.<sup>24</sup>

Contribute to the development of common data elements for cross-cultural comparisons to problem-solve shared challenges. While recent examples exist from the health services research sector on nursing home care, <sup>25</sup> we have yet to endorse common data elements of person-centered nursing practice and related contextual factors in nursing homes. However, the capacity to do so exists across our countries collaboratively, drawing upon extant nursing research. <sup>26,27</sup>

As part of the US Patient Protection and Affordable Care Act's triple aim of better care, better population health, and lower cost, <sup>28</sup> policymakers and providers alike require new approaches to organizing long-term care. Cross-comparative research has the potential to inform country-specific models of care by describing how alternative approaches accomplishing high quality, person-centered care have been achieved in the US and EU, which may be generalized to other countries that are focused on developing or improving their long-term care systems. The EU's Social Protection Committee Working Group on Ageing has identified a significant gap in the exchange of best practices of long-term care services and organization across countries, preventing countries from building evidence and learning new approaches to care. <sup>5</sup> Therefore, addressing this gap is essential if both the US and EU are to meet the needs of an aging population in an economically sustainable way that supports and honors personhood.

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