

## It's Not a Small World After All

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The article by Morris and colleagues in this issue of *JAMDA*, entitled “Hearing the Voice of the Resident in Long-Term Care Facilities – an Internationally Based Approach to Assessing Quality of Life,”<sup>1</sup> underscores the importance of including residents’ perspectives regarding the care they receive. InterRAI, an international research collaborative, developed a Self-Report Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF) which assesses resident perspectives on subscales reflecting social life, personal control, food, caring staff, and staff responsiveness. The results are based on reports of more than 16,000 residents who resided in 355 LTCFs; 44% of the respondents are from Belgium (residing in 70% of the LTCFs in the study), 32% are from Canada, 21% are from the United States, and fewer than 1% are from each of Poland, Estonia, South Africa, the Czech Republic, and Australia. Based on the distributions of the data, the researchers collapsed the scores (i.e., never/rarely; sometimes; most of the time; always); established benchmark standards for subscales; and compared scores to a single item (home-likeness) that was considered to represent an overall measure of “personal quality of life.” This study is valuable in its findings as well as in the issues it raises inherent to cross-cultural research: with long-term care a reality around the world, to what extent is research on care systems broadly generalizable?

Obtaining perspectives directly from residents is important, and since 2010 has been a standard part of screening in the U.S. Minimum Data Set 3.0 Resident Assessment Instrument (MDS 3.0 RAI) for nursing homes.<sup>2,3</sup> However, not all residents are able to self-report, and in the interRAI effort, those with more severe cognitive impairment were excluded from participation. Although it may be challenging to “hear the voice” of these

individuals, research has found that with focused interview techniques and simplified questions and response options, residents with severe dementia are able to report on their experiences;<sup>4</sup> their inclusion is important in future comparative research, especially because the needs of these individuals is largely unknown.<sup>5</sup> More so, and in the context of the Morris work, it is likely that these individuals would rate quality even lower on the two subscales that already evidenced poorer quality -- social life (e.g., meaningful activities, enjoyable things on weekends) and caring staff (e.g., staff acting on resident suggestions, asking residents how they might meet their needs) -- given that residents with dementia are less able to initiate activities or connections than others. There are potential remedies to improve care in these areas for residents with dementia, such as Namaste Care which has shown promise in small studies in the United States and United Kingdom.<sup>6,7</sup>

Another contribution of the Morris work is relating the scores on the quality of life subscales to the subjective rating of home-likeness, given that the items themselves (e.g., can participate in religion, easily go outdoors) may or may not be important to a given individual. As subscale scores increased, so too did ratings of home-likeness, which is as one might expect. On the other hand, a study on care and dying conducted in LTC settings in the U.S. and the Netherlands found a discrepancy between individual item ratings and a global rating,<sup>8</sup> suggesting that a subjective rating of quality provides information above and beyond the ratings of individual items, and may tease out cultural differences.

There is much to be learned from international data and comparisons, because they can suggest approaches to care delivery that might serve as models for other countries.

*JAMDA* has been an increasingly valuable outlet for such information, with at least nine other papers reporting data from multiple countries in the recent past.<sup>9-17</sup> That said, it is necessary that such research be mindful of important differences in culture and the organization of health care delivery if the results and interpretations are to be valid and optimally informative. In addition, certain methodological considerations are especially relevant for research comparing international data.

There is no question that culture affects the very fabric of being and daily events, but it is poorly understood and understudied in relation to health care and care delivery. As a case in point, the eight countries in the Morris et al. study vary in ways that may influence the ratings, and therefore the interpretations, of the quality of life subscales. For example, one item on the social life subscale is the extent to which an individual can participate in religion. Given that 75% of the people in the Czech Republic consider themselves to be atheist or not religious, the relevance of this item – and therefore the extent to which it conveys quality of life – may be quite different from respondents in South Africa, where only 8% consider themselves atheist/not religious (see Table).<sup>18</sup> Similarly, the item on the personal control subscale relating to the extent to which it is easy to go outdoors may matter more for those in Poland (where 39% reside in rural areas) than in Belgium (where 2% reside in rural areas).<sup>19</sup> So, as intimated above, these items may not validly constitute quality of life across different countries.

Of course, the statistics above are generalizations. Twenty-three percent of people in the Czech Republic consider themselves to be religious, and so individual-level data are needed to understand the relationship between preferences and perceptions of quality. Researchers understand the importance of examining individual-level correlates of care

needs, provision, and outcomes, but doing so may be challenging when using large international datasets that lack such granularity – as was the case in the Morris et al. study. Encouraging the development of larger databases for international research would allow more valid comparisons and elucidate when differences are and are not significant, and, if also guided by pre-conceived analytic plans, perhaps reduce publication bias in which only positive findings are reported.

A second important consideration when making international comparisons is that detected differences may reflect cultural roots and preferences intertwined with organizational practices. Taking end-of-life care as an example, and extending beyond the focus of the Morris study, 22% of people in Portugal consider their own home as the least preferred place of death (compared to 4%-11% of people in England, Flanders, Germany, Italy, the Netherlands, and Spain), perhaps due to limited palliative care available in private homes.<sup>20</sup> In terms of actual site of death, markedly more dementia-related deaths occur in hospitals in South Korea (74%) compared to the Netherlands (2%), pointing to organizational differences in care provision.<sup>13</sup> It may be challenging to disentangle cultural from care practice differences – especially given that care practices themselves are influenced by and influence cultural values. A case in point in this regard is the more cautious use of sedation in the United Kingdom compared to Belgium and the Netherlands, because in the U.K. it is seen to hasten death rather than relieve suffering.<sup>21</sup>

Of course, there are regional and cultural differences *within* countries as well, indicating the importance of recognizing and reporting such variability. For example, not only do perception of pain and pain intensity vary by ethnic group within a country

(being higher among certain minorities in the U.S.),<sup>22</sup> they also vary by location.

Canadian residents in Ontario nursing homes have more pain than do those in Saskatchewan and Manitoba.<sup>23</sup> In U.S. nursing homes, the prevalence of substantial pain varies from 0% to 55%, and is higher in not-for-profit and lower in rural homes.<sup>24</sup> But, rather than flock to nursing homes in Saskatchewan, Manitoba, or rural areas of the U.S., it is important to consider that although low levels of pain may reflect appropriate treatment, they also may reflect cultural differences in pain perception, communication, and treatment preferences; inadequate assessment; or variability in nursing home admission criteria. Thus, comparisons and conclusions must be made with caution.

A third important point relevant for international comparative research is the matter of research methods, most especially measurement and analysis. Here, three methodological cornerstones can guide such research.

Evaluate the validity of common measures across cultures. Researchers commonly examine the validity of measures used across different countries, as has been done for aggressive<sup>25</sup> and agitated<sup>26-29</sup> behaviors, depression,<sup>30</sup> neuropsychiatric symptoms,<sup>31</sup> morale,<sup>32</sup> person-centered care,<sup>33</sup> sarcopenia,<sup>34,35</sup> and measures of care quality, such as end-of-life care,<sup>36</sup> as well as numerous others.

Develop measures from the outset on an international sample. The interRAI develops measures using international samples, as was done by Morris and colleagues for the quality of life subscales. Other examples of international-based measurement development include an algorithm to predict falls<sup>37</sup> and an assessment of health care needs.<sup>38</sup> When developing such measures, it is important to consider the size of the sample contributed from different countries. Almost half of the sample in Morris' work

represented Belgium, and it is conceivable that a different factor structure might have evolved had the participation of other countries been more balanced; a sensitivity analysis might have shed light on this matter. Similarly, the distributions of the resulting data might have differed, and so might have the cutpoints and related benchmarks.

*Pool new/existing datasets in culturally sensitive ways.* Pooling (i.e., merging) data increases statistical power and the ability to compare outcomes across settings and by subgroups and countries, perhaps suggesting robust opportunities to improve care; that said, challenges to pooling data include being unable to address differences in the study populations due to, for example, no overlap in relevant variables, and lack of comparability between the items in the research instruments or their interpretation.<sup>39</sup>

What then, are the take-away points regarding international research on post-acute and long-term care medicine? First, such research is valuable. It is beneficial to examine differences across countries; to the extent that care needs differ, or processes of care differ, modifiable conditions and practices have been uncovered. Second, such research should not focus exclusively on comparing the same conditions or practices across countries; instead, new models of care also merit examination (with or without comparison), such as dementia villages in the Netherlands,<sup>40</sup> outsourcing long-term care to countries such as Mexico,<sup>41</sup> and obtaining live-in care workers from abroad.<sup>42</sup> And third, such research must be exquisitely sensitive to contextual differences that may drive or be masked by the findings, especially for older adults who have been long-influenced by local cultural circumstances. Although the world has become increasingly global, differences within and across people, and within and across countries, suggest that when all is said and done, it's not a small world after all.

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Table.

Percent of People Reporting Being Atheist or Not Religious, and Living in a Rural Area, by Country.

	Percent Atheist/Not Religious*	Percent of Rural Population†
Australia	58%	10%
Belgium	48%	2%
Canada	53%	18%
Czech Republic	75%	27%
Estonia	Not reported	33%
Poland	12%	39%
South Africa	8%	35%
United States	39%	18%

\* Gallop Poll Data, 2015.

† World Bank Data, 2016.