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Original Study

Hearing the Voice of the Resident in Long-Term Care Facilities—An Internationally Based Approach to Assessing Quality of Life

John N. Morris PhD, MSW[a,*], Anja Declercq PhD[b], John P. Hirdes PhD, FCAHS[c], Harriet Finne-Soveri MD, PhD[d,e], Brant E. Fries PhD[f,g], Mary L. James MA[f], Leon Geffen MBChB, FCFP[h,i], Vahe Kehyayan PhD[j], Kai Saks MD, PhD[k], Katarzyna Szczerbińska MD, PhD[l], Eva Topinkova MD, PhD[m,n]

[a] *Hebrew Senior Life, Boston, MA*
[b] *LUCAS and Faculty of Social Sciences the Katholieke Universiteit Leuven, Belgium*
[c] *School of Public Health and Health Systems, University of Waterloo, Waterloo, Canada*
[d] *Hospital, Rehabilitation, and Care Department, City of Helsinki, Helsinki, Finland*
[e] *National Institute for Health and Welfare, Helsinki, Finland*
[f] *Division of Geriatrics and Palliative Care, University of Michigan, Ann Arbor, MI*
[g] *Ann Arbor VA Healthcare Center, Ann Arbor, MI*
[h] *Sampson Institute for Ageing Research, Cape Town, South Africa*
[i] *Institute of Ageing in Africa, Faculty of Health Sciences at University of Cape Town, Cape Town, South Africa*
[j] *University of Calgary in Qatar, Doha, Qatar*
[k] *Department of Internal Medicine, University of Tartu, Estonia*
[l] *Unit for Research on Aging Society, Department of Sociology of Medicine, Chair of Epidemiology and Preventive Medicine, Medical Faculty, Jagiellonian University Medical College, Krakow, Poland*
[m] *Department of Geriatric Medicine, First Faculty of Medicine, Charles University in Prague, Prague, Czech Republic*
[n] *Faculty of Health and Social Sciences, South Bohemian University, Ceske Budejovice, Czech Republic*

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A B S T R A C T

Objectives: interRAI launched this study to introduce a set of standardized self-report measures through which residents of long-term care facilities (LTCFs) could describe their quality of life and services. This article reports on the international development effort, describing measures relative to privacy, food, security, comfort, autonomy, respect, staff responsiveness, relationships with staff, friendships, and activities. First, we evaluated these items individually and then combined them in summary scales. Second, we examined how the summary scales related to whether the residents did or did not say that the LTCFs in which they lived felt like home.

Design: Cross-sectional self-report surveys by residents of LTCFs regarding their quality of life and services.

Setting/Participants: Resident self-report data came from 16,017 individuals who resided in 355 LTCFs. Of this total, 7113 were from the Flanders region of Belgium, 5143 residents were from Canada, and 3358 residents were from the eastern and mid-western United States. Smaller data sets were collected from facilities in Australia (20), the Czech Republic (72), Estonia (103), Poland (118), and South Africa (87).

Measurements: The interRAI Self-Report Quality of Life Survey for LTCFs was used to assess residents' quality of life and services. It includes 49 items. Each area of inquiry (eg, autonomy) is represented by multiple items; the item sets have been designed to elicit resident responses that could range from highly positive to highly negative. Each item has a 5-item response set that ranges from "never" to "always."

Results: Typically, we scored individual items scored based on the 2 most positive categories: "sometimes" and "always." When these 2 categories were aggregated, among the more positive items were: being alone when wished (83%); decide what clothes to wear (85%); get needed services (87%); and treated with dignity by staff (88%). Areas with a less positive response included: staff knows resident's

Partial support for this study was provided by interRAI (an international nonprofit organization that provides free use of its tools to governments and care providers in exchange for the use of their de-identified data). The secondary data came from interRAI fellows from surveys completed in their countries. In addition, the Canadian research was funded by the Canadian Institute for Health Information. In Poland the data has been collected in the frame of the Jagiellonian University research grant.

The authors declare no conflicts of interest.

* Address correspondence to John N. Morris, PhD, MSW, Hebrew Senior Life, IFAR, 1200 Centre St, Boston (Roslindale), MA 02131.
E-mail address: jnm@hsl.harvard.edu (J.N. Morris).

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life story (30%); resident has enjoyable things to do on weekends (32%); resident has people to do things with (33%); and resident has friendly conversation with staff (45%). We identified 5 reliable scales; these scales were positively associated with the resident statement that the LTCF felt like home. Finally, international score standards were established for the items and scales.

Conclusions: This study establishes a set of standardized, self-report items and scales with which to assess the quality of life and services for residents in LTCFs. The study also demonstrates that these scales are significantly related to resident perception of the home-like quality of the facilities.

As we age, there may come a time when, as a consequence of physical or cognitive loss, the support of others becomes integral to our daily life.[1–3] Typically, a family member will step in to help, and over time, if capacity declines, family involvement will increase. For some, there may come a time when the decision is made to move into an assisted living environment, and finally, to a long-term care facility (LTCF). This progression is not without its consequences. Residents in such facilities may lose control of their lives, depression and social isolation may become more common, and they may come to believe that they are not respected or valued by those around them.[4–8] It is, therefore, crucial that we develop methods to evaluate residents' quality of life (QOL) in LTCFs.

LTCFs are often criticized for not providing a home-like environment.[9,10] Older people do not typically wish to live in what they perceive to be "over-controlled" institutions, with fixed schedules of daily activities, shared congregate space, and organized nursing oversight.[11–13] It is common knowledge that older adults have such views and that such facilities exist. The culture change movement of the past few decades has aimed to reverse how residents of LTCFs perceive their lives, stressing improvements in both the physical and social environment, the quality of care provided, enhanced resident autonomy, noninvasive staff support, and humane care. Nursing home initiatives to improve care have been suggested and documented by many investigators.[14–21]

Powell Lawton[22] in his early work defined quality of life of older people as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current, and anticipated." Current "reality" and future projections drive the person's sense of fit in such a facility. The literature suggests that a particular set of issues need to be assessed to understand the lives of residents in LTCFs.[23] At an operational level, however, models to describe the more specific dimensions of quality for LTCF residents vary.[24–26] At a minimum, there is consensus that to understand how the resident feels, the source of the data must be the person[27,28] and what we ask must have meaning.[29,30] In addition, measures must address issues pertinent to what Lawton called the interface between the person and the environment,[22] including measures that relate to personal quality of life and the quality of care provided to the person. Defining and measuring quality of life for persons in LTCFs is, thus, complex and multidimensional.

In this context, our report examines how LTCF residents view their life and the care they receive. Our first aim is to describe the steps taken to create a new self-reported quality of life instrument (the interRAI SQOL), which includes a series of subscales for use in LTCFs. The items in this instrument are captured in a short, interviewer-administered self-report survey created by the interRAI international research collaborative with over 100 fellows in 34 countries (www.interrai.org) and applied to a cross-national sample of LTCF residents. This survey, described later, focuses on how residents perceive the life they live and the services they receive, examining issues of privacy, food, security, comfort, autonomy, respect, staff responsiveness, relationships with staff, friendships, and activities.[31] Under this initial aim, we first evaluate these items both individually and as they are combined in a number of summary scales. This step results in the creation of a series of unique, reliable measures of quality of life and services for residents of LTCFs.

Under our second aim, we examine how these quality of life and service scales relate to whether the resident "self-reports" that the LTCF in which they reside feels like home. By this comparative analysis of the single subjective measure on whether the site is home like and the 5 scales, we are able to illuminate specific aspects of life in an LTCF environment that contribute to the feeling of being "home."

Methods

Survey Instrument

The interRAI Self-Report Quality of Life Survey for LTCF (SQOL-LTCF) is part of a larger suite of quality of life tools developed by interRAI for use across a variety of settings including home care, mental health facilities, and independent living facilities. As is the case in other interRAI instruments, the SQOL-LTCF employs both "core" items included in all the surveys designed for multiple sectors, as well as items specifically aimed at LTCF residents.[26]

The instrument was developed over several years and in a number of steps. The initial work for this effort occurred in the United States by investigators at the University of Michigan (James and Fries) and Hebrew SeniorLife in Boston (Morris); each site reviewed the literature, created items, and tested them through pilot studies.

These pilot data were next shared with a cross-national interRAI work group, tasked to create the larger suite of survey tools. This work group again reviewed the literature, identified key domains, considered the existing draft items, and created an instrument draft that was likely to elicit resident responses that would range from highly positive to highly negative.

This draft tool was next reviewed by the full interRAI international fellowship, representing persons with a diverse set of clinical and research backgrounds (www.interrai.org). Domains and items were reworked based on this input. interRAI fellows implemented projects to administer the draft instrument in their countries.[26,28,32] Following this field process, we performed quantitative evaluation of psychometric properties of the survey and evaluated qualitative feedback to complete the current version of the survey tool.[31]

Data

The data used in this report include a small number of surveys from early adopters and a more extensive cohort of survey data from facilities in Europe (Belgium),[33,34] Canada,[26,28,32] and the United States. For inclusion in the sample, the residents had to have the ability to understand and respond to the questions.

In total, surveys are available for 16,017 LTCF residents. These data include 7113 residents from 249 residential facilities in the Flanders region of Belgium, 5143 residents from Canada, and 3358 residents from the eastern and mid-western United States. Smaller data sets, sometimes from a single facility, were collected from early adopters in