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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

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A B S T R A C T

Keywords:

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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 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.

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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.

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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 Lawton²² 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

Australia (20), the Czech Republic (72), Estonia (103), Poland (118), and South Africa (87).

The 16,017 individuals surveyed reside in a total of 355 facilities. Of this total, 249 facilities were in Belgium, 51 in the United States, 46 in Canada, 3 in Estonia, 2 each in Poland and the Czech Republic, and 1 each in Australia and South Africa.

In these applications, the instrument was administered by a trained interviewer as a standard part of the facility's quality assurance program effort. As such and to protect resident anonymity, we were unable to gather information on resident demographics; thus, we are unable to report, for example, on sex, age, and marital status. Residents were asked to participate but were clearly informed that they could decline without any consequences. The training of surveyors occurred separately in each country, but in each instance followed the model training protocol specified by interRAI.³¹ Interviewers asked residents for their opinions on the items as phrased. Excluded were approximately 20% to 35% of the residents in a typical LTCF who could not respond to the interviewer, usually because of their cognitive deficits as measured by the interRAI Cognitive Performance Scale, the equivalent of a Mini-Mental State Examination score of about 10 or lower.³⁵

Approvals for analysis were obtained from the Institutional Review Boards of the University of Michigan, University of Waterloo, and Hebrew SeniorLife, and relevant ethical research committees according to rules in other countries.

Analysis

The analysis for aim 1 proceeded through a multistep process. First, we assessed the distributional properties of the 49 items of the SQOL-LTCF across the 5 response categories which range from “never” to “always.” Because the most frequent responses were in the “sometimes” to “always” range, and much less frequently at the other end of the scale continuum, we collapsed the score range, with “never” and “rarely” assigned the value 0, “sometimes” a score of 1, “most of the time” a score of 2, and “always” a score of 3. Second, we used factor analysis (with a varimax rotation of the principal component factor solution) to assess how the items clustered within distinct conceptual domains. This allowed us to create summary scales by adding the collapsed scores of items that clustered. We

then examined the distribution of these scales for reasonably broad dispersion. Third, we calculated the Cronbach's alpha for each summary scale to assess its internal consistency, using a minimum value of 0.70 to be accepted. The alpha statistic has a possible range of from 0 to 1.0, and it is generally accepted that for a summary scale to be usable in real-world applications the scale must have a minimum value of .70. More specifically, acceptable scales have an alpha score range of from .70 to .79, good scales have a score range from .80 to .89, and excellent summary scales have a score range of .90 or higher.

Fourth, we computed standard distributional properties for each item and each scale at the 20th, median, and 80th percentile across the facility sample, and report these values for the scales (distributional properties for the individual items are available from the corresponding author).

In the following, we describe how respondents differed across the items within each scale domain, and then across scale domains.

Finally, under aim 2, to identify which summary scales were most associated with quality of life, we assessed how the scales related to the resident self-report item “this place feels like home to me.”

Results

The factor analysis of the 16,071 SQOL-LTCF surveys identified a total of 5 scales, representing separate domains of quality of life. Three scales reference how residents perceive their usual quality of life—the Social Life Scale, Personal Control Scale, and Food Scale; the 2 remaining scales reference aspects of care—the Caring Staff Scale and Staff Responsiveness Scale. Figures 1–5 display the items involved in each of the 5 scales, providing for each item the percent in the “most of the time” and “always” categories. Table 1 provides characteristics of the 5 scales, including for each the scale range, mean and standard deviation (SD), median and 20th to 80th quintiles (Q₂₀–Q₈₀) of facility level mean scores, and Cronbach's alpha.

Social Life Scale

Figure 1 describes the items in the 10-item Social Life Scale, including activity participation, friendship, interests, and engagement

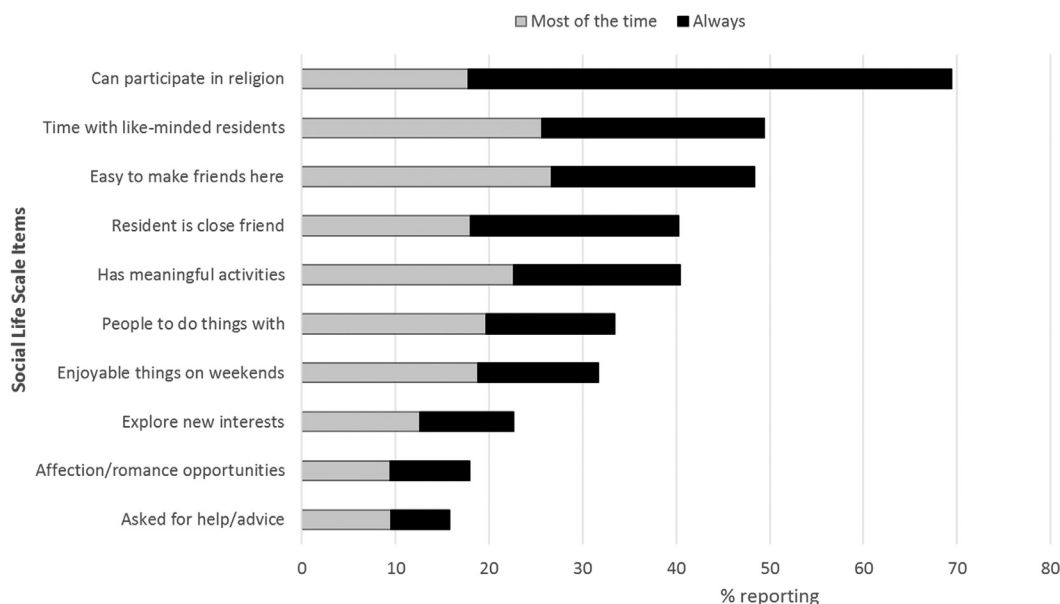


Fig. 1. Social Life Scale: Percentage of residents reporting statements to be true “most of the time” or “always.”

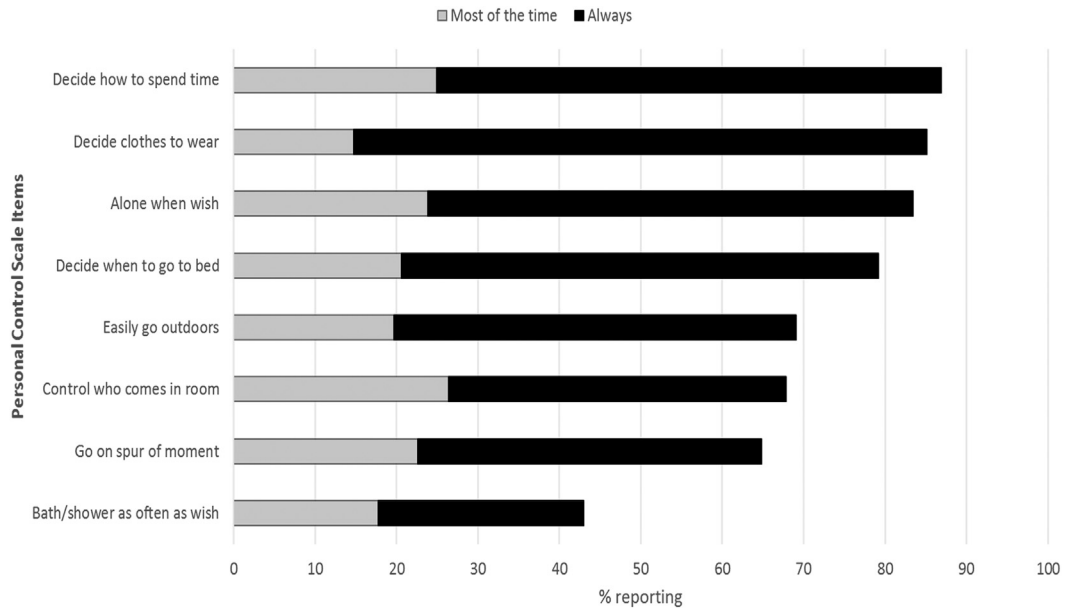


Fig. 2. Personal Control Scale: Percentage of residents reporting statements to be true “most of the time” or “always.”

with others. The scale is highly reliable (Cronbach’s alpha = 0.80). One-third or more of residents on 7 of the 10 items responded that these positive conditions are present most or all of the time. An average of less than 1 in 5 residents (18%) reported that these conditions were always relevant to their daily lives now that they are in a LTCF. However, residents were not always in contact with friends and they did not always find it is easy to make friends (78%). In addition, they did not always have meaningful things to do (81%) or enjoyable things to do on weekends (87%).

When the collapsed scores for these 10 items in this area are summarized, the Social Life scale has a possible range of 0–30 (where 30 would be the most positive); the observed mean score of 12 is slightly more positive than the midpoint on the scale (11.7) and the scale is skewed toward lower values (not shown).

Personal Control Scale

Figure 2 displays the 8 items in the resident Personal Control Scale. For 7 of the items, 40% or more of the residents reported that the condition always applies to their daily life. The items reference discrete choices residents make without the help of others (eg, how to spend time, what clothes to wear; when to go to bed) and daily control over their movements (eg, when to be alone, easy to go out). About 70% or more of the residents reported that they had control in these areas most or all of the time. For 5 items, one-half or more of the residents also reported that this was always true in exercising these choices. The items with a relatively lower percent of positive responses included controlling who came into their room, going out on the spur of the moment, or deciding when to bathe or shower. The

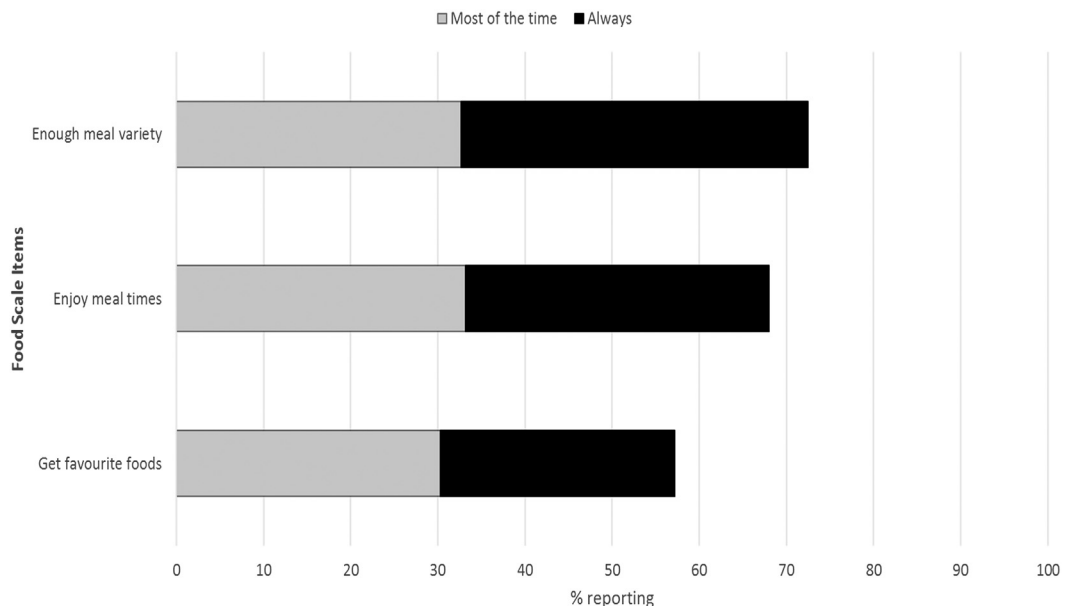


Fig. 3. Food Scale: Percentage of residents reporting statements to be true “most of the time” or “always.”

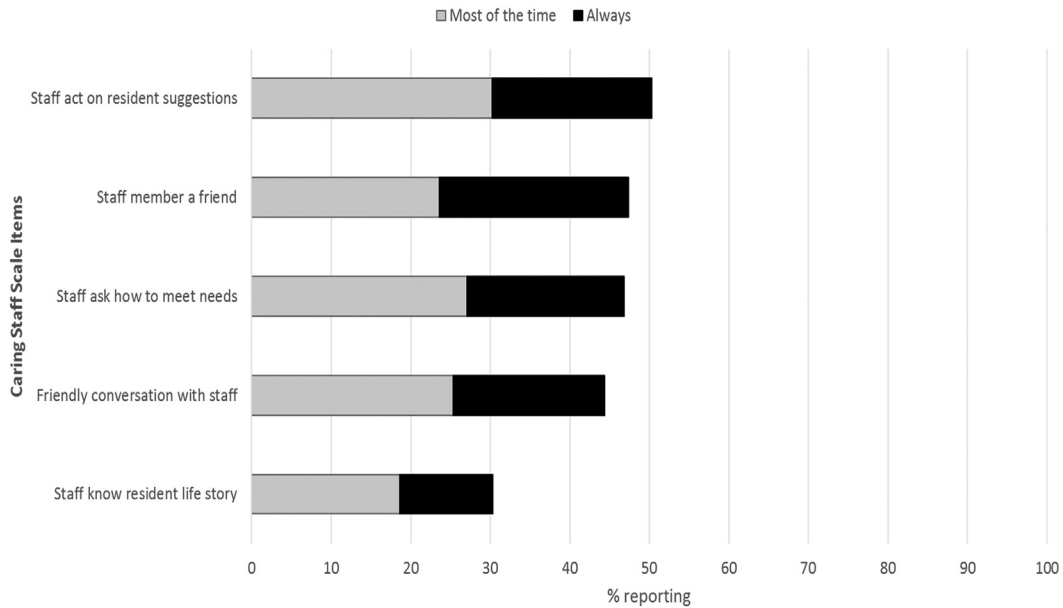


Fig. 4. Caring Staff Scale: Percentage of residents reporting statements to be true “most of the time” or “always.”

latter of these items was the most problematic for residents in the data collected; only 25% reporting that they always had control of when they took a bath or shower.

The Personal Control Scale was formed by summing up the collapsed scores for these 8 items. The scale has a possible range of 0 to 24 and an acceptable Cronbach’s alpha reliability level of 0.76. The observed mean scale score in our sample was 16.

Food Scale

Figure 3 describes the 3-item set that references how residents perceive their quality of life and services in relation to the food served. Forty percent of residents reported they always had enough variety in their meals, 35% always enjoyed mealtimes, and 27% always got their favorite foods. When we added those who responded “most” of

time or “always,” the percent of positive responses ranged from 57% to 73%. A Food Scale summing these 3 rescored items ranged from 0 to 9, with a mean of 6.5, and had a Cronbach’s alpha of 0.80.

Figures 4 and 5 move from residents’ perceptions of their personal quality of life to their perceptions concerning staff and the services they receive.

Caring Staff Scale

Figure 4 includes 5 items that focus on what we have labelled as “Caring Staff.” On average only a little over 40%–50% of residents said that these statements were true most or all of the time. The highest positive response was for the item that asked whether staff acted on resident suggestions: 20% said “always” and 30% “most of the time.” Other items with similar response frequencies included whether a staff

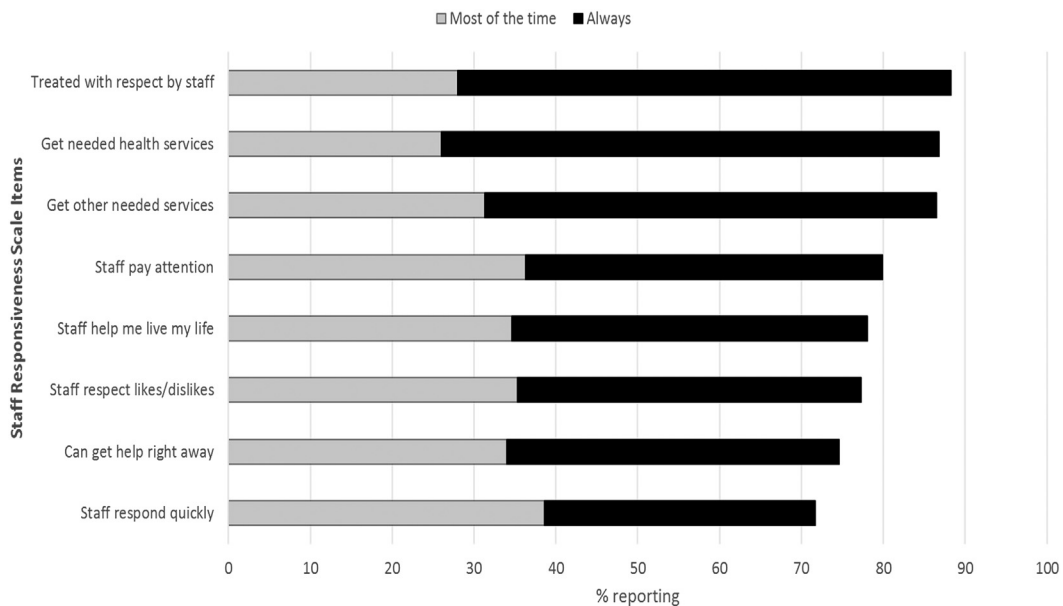


Fig. 5. Staff Responsiveness Scale: Percentage of residents reporting statements to be true “most of the time” or “always.”

Table 1
Distributional Properties and Internal Consistency of interRAI QOL-LTCF Scales

Scales	Range	Sample Mean (SD)	Facility Median (Q ₂₀ –Q ₈₀)	Cronbach's Alpha
Social Life	0–30	12.0 (6.6)	11.7 (9.0–13.9)	0.80
Personal Control	0–24	16.4 (5.5)	17.3 (14.2–19.5)	0.76
Food	0–9	6.5 (3.0)	6.6 (5.2–7.8)	0.80
Caring Staff	0–15	6.9 (3.7)	6.9 (5.0–8.6)	0.73
Staff Responsiveness	0–24	17.8 (4.9)	18.8 (16.3–20.6)	0.86

member was a friend, whether staff asked how needs could be met, and whether the resident and staff had friendly conversations. The item with the lowest positive response was whether staff knew the resident's life story, which was “always” true for only 12% of residents.

Given these distributions, the total scale mean of 6.9 is just slightly lower than the midpoint in the 0–15 score range, and the scale has a Cronbach's reliability of 0.73.

Staff Responsiveness Scale

Figure 5 references 8 items associated with Staff Responsiveness, which we formed into a scale with a very reliable Cronbach's alpha 0.86. Of the 5 scale domains reported in this report, residents rated these items most positively. Adding the “always” and “most of the time” rating, on average about 80% of residents reported staff acted responsively on all 8 measures. More specifically, the residents were treated with dignity by staff, they got the health services they needed, and in general they got the services they needed. The lowest positive response ratings in this domain were for how quickly staff respond: 39% reported staff always responded quickly and 33% said staff responded quickly most of the time. The overall scale mean was 17.8, which is about three-quarters the way along the 0–24 point score continuum (where, once again, a high response is best).

Association With “Feels Like Home”

The next analyses, under aim 2 of this report, demonstrates that there is a strong relationship between how these subjective quality of

life and services scales relate to residents' perception of the “home like feel” in their current LTCF. Residents who said that the facility “never/rarely” felt like home had much lower mean scores on the 5 QOL scales (Figure 6) (note all relationships are significant at .001 or lower). For example, on the Social Life Scale where the mean equaled 12.0 (on a scale that has a range of 0–30), residents who said that where they lived “never/rarely” felt like home had a mean Social Life Scale score of 8.6. This score is 3.4 points (0.51 SDs) below the grand mean.

Conversely, residents who reported that the facility “always” felt like home had much higher mean scores on all 5 of these scales and on a parallel item that is not shown: the “would you recommend the site to others.” These residents had an average scale score that was one-third to about one-half of a SD above the grand mean for the scales. For example, on the Staff Responsiveness Scale where the grand mean equaled 17.8 (on a scale that has a range of 0–24), residents who said the LTCF in which they lived “always” felt like home had a mean Staff Responsiveness Scale score of 20.6 (2.8 points higher and 0.56 SDs above the grand mean).

Benchmark Standards for the QOL Scales

With 355 LTCFs represented in our data, it was possible to develop benchmarks for our 5 subjective quality of life scales. In Table 1, we presented 3 facility benchmark standards for each measure: the 20th percentile (the lower performing sites), the median (the average performing sites), and the 80th percentile (the top performing sites). For example, the standards for the Personal Control Scale are as follows: 20th percentile = 14.2, median = 17.3, and 80th = 19.5. Thus, for this measure there is a 5-point difference between the 20th and 80th percentiles.

In a similar way, it is also possible to benchmark the performance of individual items from the survey. For example, Figure 7 shows the percentage of residents reporting that they “would recommend the site to others” in 41 Canadian homes, compared with the international benchmarks for that item obtained from this study. The international median was about 80% reporting the statement to be true most or all of the time. The lower benchmark (Q₂₀) was about 68% and the upper benchmark (Q₈₀) was over 90%. Most of the Canadian homes fell within the benchmark range, but 10 homes were at or below the 20th

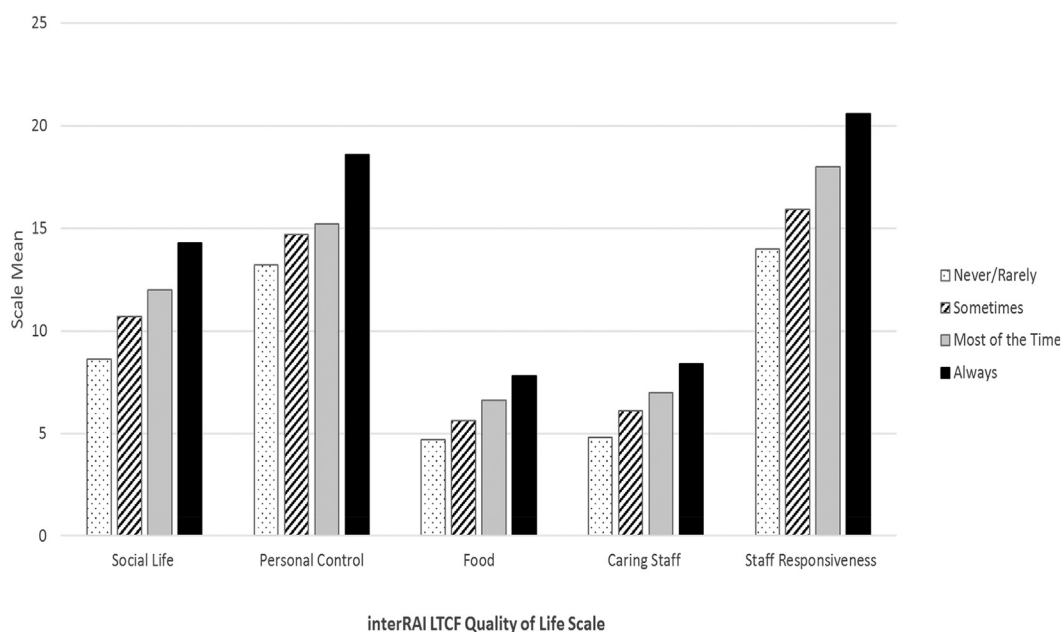


Fig. 6. Mean LTCF Quality of Life Scale Scores by residents' ratings of the “feels like home” item.

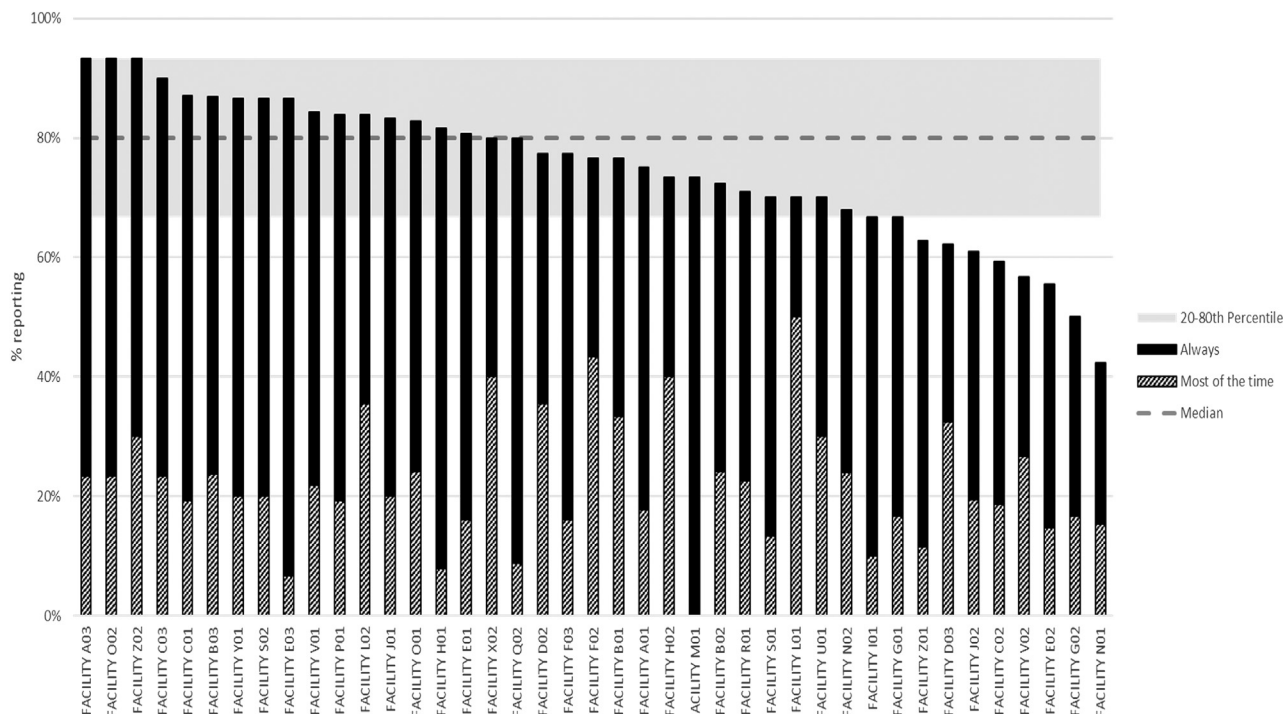


Fig. 7. Benchmarking Report for “would recommend site to others”: Mean facility rates (9 nations) of residents responding “most of the time” or “always” compared with the median and 20th–80th percentiles of all facilities.

percentile of the international distribution. Benchmark standards for the individual items are available from the corresponding author.

Discussion

The interRAI SQOL-LTCF has undergone a long period of international development and testing. Pilot studies were carried out in multiple nations, and it is now in use as a truly international tool in LTCF facilities in North America—facilities in Massachusetts and several Canadian provinces, Europe—all Flemish facilities in Belgium, most facilities in Finland, South Africa—1 facility in Cape Town, and New Zealand—all facilities.

LTCFs serve older residents, and especially the oldest-old in our society: those with challenged functional and cognitive status, and complex health and mental health needs. Seen from this perspective, the proportion of persons over 65 years of age in LTCFs varies by country.^{36–38} Examples include: 8.0% in Iceland; 5.9% in Flanders and the United States; 4.0% in Denmark; 2.3% in Estonia; and 2.0% in the United Kingdom and Sweden. Residents stay for several weeks to years, and for many the LTCF will be the last place they live. As such, this residential alternative, at this point in the life of the person, has great meaning. The research in this report assesses how residents in such residential facilities perceive their life (3 scales) and services (2 scales). We know that most would not have preferred to spend their end of days in such a setting, but once there, what can our data tell us about the quality of that life?

First, residents indicated that they had a caring staff. Positively, about 80% of the residents surveyed reported that staff were responsive most or all of the time. Almost 90% of the residents reported they were treated with dignity, and 60% reported that this applied all the time. Similarly, 86% of the residents received the services they need, with about 60% saying that this was always true.

At the same time, for the second service related scale, only about one-half or fewer of the residents said that staff were caring all or most of the time. Thus, although the resident perceived that their

service needs were being met, the response by staff was more task related than personal. In this vein, only about 45%–50% of residents said that staff act on their suggestions or that staff ask the resident how they might meet their needs. Only a minority of residents said that a staff member is a friend (with 24% saying this was always true). Finally, only 12% of residents said that a staff knows the story of the resident’s life. Thus, although residents reported that they were respected and they received the services they needed, the nature of their relationship may be characterized as formal rather than personal. For approximately 1 in 2 residents, staff follow the “letter-of-the-law” when it comes to service provision and fail in reaching out to residents to better understand their history, individual needs, and preferences.

Residents had a mixed reaction to the food they received. Although having food choices are basic expectations of all of us, in the facilities included in our study residents’ responses are quite mixed and the challenges are real (eg, residents’ reaction to their medication can affect how they perceive the food they consume, as can age-related loss of taste). Only 27% of the residents always get their favorite foods, and including the responses of those who said “most of the time”, the percent of positive responders rises to only 57% of all residents. The response is a little more positive when residents were asked whether they received enough variety in their meals; 73% said this was true most or all of the time.

In terms of personal control, an area in which there has been a heightened interest over the past few decades, facilities seem to be reasonably responsive. On average, a little over 70% of residents responded that they had personal control over key activities most or all of the time. Over 80% said they could be alone when they wanted, they could decide the clothes they wore, and decide how to spend their time. At the other extreme, there was only 1 area in which residents said that they really lacked control: only 43% of residents said that they could decide when to bathe most or all of the time. Institutional rules, whether rational or not, seem to be the more prevalent driving force in this one area. In all other areas, the typical facility has

found a way to be responsive to the natural desire of adults to have a reasonable level of control over their lives.

Of all of the questions asked in our survey, the 10 in the Social Life domain provided the most disturbing responses, with as low as 16% given a rating of “most of the time” or “always” for the items involved. The 1 exception is the question of the resident’s being able to participate in religious activities that had meaning to the resident, where 69% said this was true most or all of the time. There may be several reasons for this finding: some facilities are supported by religious denominations, others may have scheduled times for religious services or chaplaincy visiting programs, or perhaps more personal solutions predominate.

Of the other Social Life domain items, only 22% of the residents said that it was always easy to make friends and that another resident was a friend. Satisfaction with activity options was also problematic: 18% said they always had the opportunity to be engaged in meaningful activities; 13% always had enjoyable things to do on weekends; and 6% were always approached by others for help or advice. At the same time, such exchanges become more problematic as activities of daily living dependency and cognitive loss become more prevalent. Although these measures are not available in this study, their importance is unquestioned. This of course is no “excuse” for not trying to improve the resident’s social life. Most residents are not totally functionally impaired, most can communicate, and most retain some level of cognitive decision making. Thus, it is rather sad to think of residents who retain such skill sitting alone and unaddressed from one day to the next. Staff are not their friends and other friends have not been brought into their social lives. It appears that the next frontier for LTCFs is to identify what it will take to create the emotional climate that facilitates meaningful relationships among staff and residents, between residents, as well as maintains (or mends) long-standing social relationships with the community beyond the walls. This is a huge undertaking.

Another way to look at these data is from the perspective of residents’ perception that the LTCF feels like home, which we consider to represent an overall measure of personal quality of life. Thirty-eight percent of residents said this was always true and 25% said this was true most of the time. For residents who said that this was true all the time, we saw much higher (positive) scores on all 5 of the summary QOL scales reported in this paper. This association suggests that multiple intervention avenues may have to be followed to improve resident quality of life.

Conclusions

Societal changes have increased the need for developing methods to evaluate residents’ quality of life in LTCFs. The interRAI SQOL-LTCF instrument consists of 49 self-report items that permit us to collect data on the quality of life of residents in LTCFs. In our work, factor analysis identified a total of 5 scales, representing separate domains of quality of life and services. Three scales show how residents perceive their usual quality of life: the Social Life Scale, Personal Control Scale, and Food Scale. Two scales reference aspects of care: the Caring Staff Scale and Staff Responsiveness Scale. The study also demonstrates that the 5 scales are significantly related to resident perception of the home-like quality of the facilities. As such, these scales and the individual SQOL-LTCF items allow for benchmarking of facility quality.

LTCFs as well as governments can, thus, use this instrument to monitor and ameliorate the QOL of residents. They can also use our experience to ask where does one go from here in improving the living experience of residents in LTCFs?

We found a strong relationship between residents seeing the site as homelike and their willingness to recommend the site to others. This would seem to be the dual key: change the environment to be more home-like and strive to increase the positive response of

residents to the 5 scales reported in this report. At the same time, the operational steps will not be easy. In our work, facilities that are more home-like have a positive position on all 5 of the quality of life and services scales. To reach such an all-encompassing position one should start with a review of where a site is doing well across the 5 scale areas and where there are challenges. It is in the latter areas where a systematic improvement may be warranted.

Yes, facilities could do better, but these data suggest that whatever the future might hold, large numbers of facilities have a positive base on which to build their future corrective activities to afford residents an improved quality of life.

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