Measuring Quality of Life in LTC:
interRAI Self-reported Quality of Life Survey for Long Term Care Facilities

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Agenda

• Development of interRAI Self-reported Quality of Life Surveys

• Cross-national benchmarking QoL
  • interRAI pilots
  • CIHI study
  • Belgian implementation

• Results of SQLI pilot
Measuring Quality of Life: A Starting Point

- **Two perspectives on QoL**
  - Objective, externally-knowable aspects
    - Starvation, extreme poverty, abuse
  - Subjective, idiosyncratic, personal evaluation
    - Self-ratings, individual’s unique perspective

- **Challenge**
  - The two perspectives don’t necessarily always coincide
  - Neither perspective can be ignored
Examples of interRAI Measures of QoL:
Objective Indicators Measured in interRAI Assessments

- Pain
- Depression
- Social isolation
- Engagement
- Sleep
- Conflict
- ADL
- Sensory perception
- Cognition
- Health symptoms
- Pressure ulcers
Design Parameters for interRAI Subjective QoL Measures

- All forms self-rated (person’s perspective only)
- Multidimensional, but focus on subjective experience
  - Autonomy, dignity, choice, integration, social participation
- Builds on existing international research
  - Cross-cultural applicability essential
  - Extensive interRAI experience in QoL research
- Complements interRAI assessment instruments
  - Full suite of QoL measures, not only single sector
- Three levels of items
  - Core – all instruments
  - Optional – many instruments, but not necessarily all
  - Specialized – unique to specific service settings
Dimensions of QoL Addressed
interRAI Quality of Life Survey for LTCF

- Privacy
- Food & meals
- Safety & security
- Comfort
- Daily decision making
- Respect
- Responsiveness of staff
- Staff-resident bonding
- Activities
- Personal relationships
Response Set for QoL Items

• Each item has five response alternatives
  • 0 – Never
  • 1 – Rarely
  • 2 – Sometimes
  • 3 – Most of the time
  • 4 – Always

• interRAI reports focus mainly on percent scored 3 or 4 to indicate a positive response
Percentage of Rating Selected Items as True Most of the Time or Always, by Facility and Country, (N=2,384; 7 countries)

% Positive

Feels like Home

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Percentage of Rating Selected Items as True Most of the Time or Always, by Facility and Country, (N=2,384; 7 countries)

Bathe when want

Twitter: @interRAI_Hirdes
Percentage of Rating Selected Items as True Most of the Time or Always, by Facility and Country, (N=2,384; 7 countries)
Percentage of Rating Selected Items as True Most of the Time or Always, by Facility and Country, (N=2,384; 7 countries)

- Feels like Home
- Bathe when want
- Meaningful Activity

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Current Status of QoL Surveys

- Manual is now with publisher
  - Should be available by end of November 2015
  - Form has been translated into several languages, but manual only in English
- One licensed software vendor in Canada → Tevetra
- New implementations
  - Province of British Columbia
  - Extendicare
- Other instruments
  - Family survey
  - QoL in home care, seniors housing, assisted living, mental health

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Peer-reviewed Publications


Cross-national benchmarking of QoL

- To date there have been three large scale initiatives that have generated substantial data sets
  - interRAI pilots: various projects to implement and test earlier versions of instrument
  - CIHI study: Canadian study to test QoL survey in LTC homes, including sites in original Kehyayan study
  - Belgian implementation: 1/3 of Flemish LTC home residents surveyed on revolving 3 year cycle
Development of Summary Scales for interRAI QoL Surveys

• Derivation of scales
  • Use data from multinational pilot studies in nursing homes
    • Canada: 3,030
    • United States: 1,990
    • Other countries (Australia, Belgium, Czech Republic, Estonia, Poland, South Africa): 626
  • Validation samples: Canada (CIHI study); Belgium
  • Factor analyses yielded five scales
    • Social Life
    • Personal Control
    • Food
    • Caring Staff
    • Staff Responsiveness

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Cronbach’s Alpha Values for interRAI Self-Reported Quality of Life in Long Term Care Scales, n=372 facilities

<table>
<thead>
<tr>
<th>interRAI QoL Scale</th>
<th>Derivation Sample (n= 82 homes)</th>
<th>Belgian Sample (n= 250 homes)</th>
<th>Canadian Sample (n= 40 homes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Life Scale</td>
<td>.89</td>
<td>.77</td>
<td>.81</td>
</tr>
<tr>
<td>Food Scale</td>
<td>.82</td>
<td>.81</td>
<td>.77</td>
</tr>
<tr>
<td>Personal Control Scale</td>
<td>.86</td>
<td>.72</td>
<td>.71</td>
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<tr>
<td>Caring Staff Scale</td>
<td>.81</td>
<td>.71</td>
<td>.73</td>
</tr>
<tr>
<td>Staff Responsiveness Scale</td>
<td>.91</td>
<td>.84</td>
<td>.87</td>
</tr>
</tbody>
</table>
Distributions of interRAI Self-Reported Quality of Life in Long Term Care Items Used in Scales, \(n=372\) facilities (in 9 countries)

<table>
<thead>
<tr>
<th>Item/Scale</th>
<th>Mean (SD)</th>
<th>Median (Pctl_{20}-Pctl_{80})</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Life Scale</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can participate in religion</td>
<td>74.4 (21.2)</td>
<td>78.3 (55.4-93.3)</td>
</tr>
<tr>
<td>Time with like-minded residents</td>
<td>51.1 (19.0)</td>
<td>51.7 (36.5-66.7)</td>
</tr>
<tr>
<td>Resident is close friend</td>
<td>41.0 (17.9)</td>
<td>42.9 (24.1-55.9)</td>
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<tr>
<td>Explores new interests</td>
<td>25.9 (22.9)</td>
<td>23.3 (2.8-46.7)</td>
</tr>
<tr>
<td>Has meaningful activities</td>
<td>41.2 (17.0)</td>
<td>40.0 (26.7-55.6)</td>
</tr>
<tr>
<td>Easy to make friends here</td>
<td>49.3 (18.7)</td>
<td>50.0 (33.3-65.3)</td>
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<tr>
<td>Enjoyable things on weekends</td>
<td>30.0 (24.6)</td>
<td>28.0 (3.3-50.0)</td>
</tr>
<tr>
<td>People to do things with</td>
<td>33.9 (16.8)</td>
<td>33.3 (20.0-46.7)</td>
</tr>
<tr>
<td>Affection/romance opportunities</td>
<td>21.2 (18.4)</td>
<td>16.7 (6.7-33.3)</td>
</tr>
<tr>
<td>Asked for help/advice</td>
<td>14.2 (12.9)</td>
<td>11.5 (3.3-23.8)</td>
</tr>
</tbody>
</table>
Impact of Reference Groups on Benchmarks

MEDIAN (Q20-Q80)

Get favourite foods here
Shower/bathe as often as wish

All homes  Belgium  Canada  USA  All homes  Belgium  Canada  USA

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SQLI Pilot of interRAI Self-report Quality of Life Survey for LTCF
SQLI QoL Pilot

- 10 facilities
  - Mix of Canadian and US
  - Some sites have only pilot sample data (31-55 cases)
  - Some are single site others multi-site organizations
  - Some have larger n’s because implemented as organizational standard

- 1,365 residents
  - CPS scores range from 0-3
Staff Responsiveness Scale

- 8 items dealing with whether resident needs are met
  - can get help
  - get services I need
  - treated with respect
  - staff respect likes/dislikes
  - staff pay attention
  - care helps me live life
  - staff respond quickly
  - can get health services
Staff Responsiveness Scale

Mean scale score (SD) – Max 24

Better
Example Figure

20th - 80th Percentile and median are based on international benchmarking data.

The chart shows the percentage of responses for each category (A to J) with different levels of frequency (Often/Always) and their corresponding percentiles (20th - 80th).

Legend:
- 20-80th Percentile
- Often
- Always
- Median
I am able to get help right away if needed

Can get help right away

20-80th Percentile

Often

Always

Median

Better
The care and support I get help me live my life the way I want

25%
Personal Control Scale

- 8 items dealing with personal control
  - alone when wish
  - can go outdoors
  - can go spur of the moment
  - decide how to spend time
  - bath or shower as often as want
  - control who comes in room
  - decide what clothes to wear
  - decide when to go to bed
Personal Control Scale

Mean scale score (SD) – Max 24

A: 14
B: 16
C: 15
D: 22
E: 16
F: 16
G: 16
H: 16
I: 16
J: 15

Better
I can be alone when I wish

Can be alone

% Better

A
B
C
D
E
F
G
H
I

20-80th Percentile
Often
Always
Median

Can be alone

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I can have a bath or shower as often as I wish

<table>
<thead>
<tr>
<th>Bath/shower as often as wish</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
<th>J</th>
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<tbody>
<tr>
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Better
Social Life Scale

• 10 items dealing with an engaged, meaningful life
  • people ask for help or advice
  • enjoyable things on weekends
  • participated in meaningful activities
  • time with like minded residents
  • explore new skills and interests
  • people want to do things with me
  • affection or romance
  • easy to make friends here
  • resident is close friend
  • can participate in religious activities
Social Life Scale

Mean scale score (SD) – Max 30

Better
People ask for my help or advice

Residents asked for help or advice

Better

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Residents asked for help or advice

20-80th Percentile

Often

Always

Median

A B C D E F G H I J

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I participated in meaningful activities in the past week

Has meaningful activities

- 20-80th Percentile
- Often
- Always
- Median

Better
Another resident here is my close friend
Food Scale

- 3 items dealing with food
  - favourite foods
  - variety in meals
  - enjoy mealtimes
Mean scale score (SD) – Max 9

Food Scale

Better
Residents who enjoy meal times

I enjoy meal times

20-80th Percentile

Often

Always

Median
I have enough variety in my meals

Residents with enough meal variety

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
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<td>0%</td>
<td>20-80th Percentile</td>
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Better
Caring Staff Scale

• 5 items dealing with closeness to staff
  • consider staff friend
  • staff talk to me about my needs
  • know story of my life
  • staff friendly conversation
  • staff act on suggestions
Caring Staff Scale

Mean scale score (SD) – Max 15

- A
- B
- C
- D
- E
- F
- G
- H
- I
- J

Better
I consider a staff member my friend

Staff member is a friend

20-80th Percentile
Often
Always
Median

Better
Some of the staff know the story of my life

- Staff knows resident life story

20-80th Percentile

Often

Always

Median

Better

20-80th Percentile

Often

Always

Median
Standalone items

interRAI Self-reported QoL Survey for LTCF
I would recommend this site or organization to others

Recommend to others

20-80th Percentile
Often
Always
Median

Better
This place feels like home to me

Feels like home

Better

20-80th Percentile  Often  Always  Median

A  B  C  D  E  F  G  H  I  J

Feels like home
Bothered by the noise

I am bothered by the noise here

Bothered by the noise

Better

20-80th Percentile
Often
Always
Median

A
B
C
D
E
F
G
H
I
J

Often
Always
The food is the right temperature when I eat it

Right temperature food

20-80th Percentile  Often  Always  Median

Better