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Session 2

Quality of life measurement techniques for special populations
Structure of presentation

Problems with subjective vs. objective QOL measurement
[a key concern in the area of disability]

Problems in the construction and administration of QOL scales to special groups
Quality of Life measurement

Objective Conditions

Subjective Wellbeing

Can we use one to infer the other?
Valid SWB measurement challenges our prejudices.

Does old age and infirmity mean life is not worth living?

Infirmity is obviously a source of challenge to homeostasis.

Are old and disabled people necessarily unhappy?
Broe, et al. (1998)
International Journal of Geriatric Psychiatry, 13,667-673

Participants:
630 people aged 75+ living in the community.

Objective Health Status:

- Bone/Joint disease: 71%
- Heart disease: 45%
- Gait instability: 46%
- Chronic Lung disease: 22%
- Cognitive impairment: 38%

Summary:
Of 11 disorders measured, the average person had 3.6.
They were mainly living alone and low socioeconomic status
Poor physical health does not equate to low SWB

Implications
Provided that people have other resources, financial or relational, some people in ill-health can experience high life quality.
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Provided that people have other resources, financial or relational, some people in ill-health can experience high life quality.
Provided that people have good financial and relational resources, most people in ill-health can experience normal SWB.
Quality of Life measurement

Objective Conditions  Subjective Wellbeing

r = very low due to homeostatic management of SWB
1. To get an overall picture of QOL, both objective and subjective QOL need to be measured.

2. BUT objective data cannot be combined into a total score.
Objective indicators cannot be validly combined into a scale

Evaluate the life quality of someone who:
Has many excellent friends
Has much arthritic pain
Is very wealthy
Lives in prison

Making a scale from the average of such variables makes no sense

Each variable must be examined separately
Neither can objective and subjective data be combined. If they are combined, then the scale reflects the objective more than the subjective QOL.
Income and subjective wellbeing

Total N ≈ 28,000

Subjective wellbeing

Household Income ($'000)

- <$15
- $15-30
- $31-60
- $61-90
- $91-120
- $121-150
- $150+

*73.0
*76.5
*78.0
*78.3
79.2

Normal Range

71.7
73.9
74.9
76.5
78.0
78.3
79.2
Objective wealth can (theoretically) rise for ever, but SWB can not.
Summary

1. To get an overall picture of QOL, both objective and subjective QOL need to be measured.

2. Objective data cannot be combined into a total score.

3. Objective and subjective data cannot be validly combined
Who requires a special scale to measure subjective wellbeing?

**ONLY** people who do not have the cognitive capacity to handle the generic scale.

- Moderate intellectual disability
- Dementia
- Brain injury
- Young children
Special scales are inherently dangerous.

Major issues: (a) Interpretation of scores
(b) Scale administration
Scale score interpretation

If a scale is measuring ‘quality of life’, then the scores that indicate ‘high life quality’ should be the same for everyone.

But, the scores from special QOL scales for minority groups almost always downgrade the standard for high QOL.
Reference to sub-group norms

Medicine:
Health Related Quality of Life Scales
“How often do you vomit?”

Disability
“Can you choose what you want to eat each day?”

NB. These items represent SYMPTOMS of medical conditions or uncertain living circumstances. They do NOT represent life quality

MORAL: The criteria for judging a high quality life must be the same for everyone.
PARALLEL FORMS OF THE PWI

• The PWI-Adult (PWI-A)

• The PWI-School Children (PWI-SC)

• The PWI-Intellectual or Cognitive Disability (PWI-ID)
In order for the scores from SWB scales to be interpreted validly, scores must be referenced to general population norms.

ie. SWB scales must be equally applicable to general population samples and population sub-groups.
Issues in scale administration to people who have problems of comprehension

Pitfall #1

The assumption

The person understands what you are asking them to do
Response competence must not be assumed.

Pre-testing for response competence is vital to obtain reliable and valid data.
Personal Wellbeing Index – Intellectual Disability
3rd Edition

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MANUAL
2005
http://acqol.deakin.edu.au
Pre-Test  
(PWI-ID and PWI-PS)

Step 1: Initial selection of potential respondents

Step 2: Testing for using response scale competence  
[if testing shows a lack of competence]

Step 3: Further testing for using a simpler response scale  
(Reduced-choice format: 5pt, 3pt, 2pt)
Ideal response scale
0 – 10 competence testing

“Can you count from Zero to 10?”

*If ‘Yes’*

“OK, can you please now count from Zero to 10.”
0 – 10 competence testing

[Explain the scale anchors]

“If you felt VERY HAPPY, where would you point?”
[Respondent must point to 10 for a correct response]

“If you felt VERY SAD, where would you point?”
[Respondent must point to zero]

“If you felt just A LITTLE BIT HAPPY, where would you point?”
[Accept any score from 6-8]
If people cannot reliably use the 0 – 10 scale, then we need to discover what complexity of scale they can use
1. Order of Magnitude Testing

E.g. “Point to the SMALLEST block”

E.g. “Point to the SECOND BIGGEST block”
3. Use An Abstract Reference

E.g. “If you felt HAPPY...which face would you point to?”

E.g. “If you felt HAPPY...which face would you point to?”
“............A LITTLE BIT SAD..........................?”
“............NEITHER HAPPY NOR SAD..................?”
Pre-testing for acquiescence
[responding in a way to please the person asking the questions]

Point to the respondent’s watch or some item of clothing.

Ask them:

• “Does that (e.g. watch) belong to you?”
• “Do you make all your own clothes and shoes?”
• “Have you seen the people who live next door?”
• “Do you choose who lives next door?”
Extent of the problem

General population samples: < 1%

People with an intellectual disability: 20 – 30%

If a respondent provides acquiescent responses what should be done?
Extent of the problem

General population samples: < 1%

People with an intellectual disability: 20 – 30%

If a respondent provides acquiescent responses what should be done?

TESTING SHOULD BE TERMINATED
Summary

Pre-testing for acquiescence is essential
Pitfall #2

The assumption

If someone does not understand a question, or the question is not relevant to them, they will let you know [instead of providing a random or acquiescent response]
General population

In 2006 we added new domain to the PWI. (Survey 16-23)
“How satisfied are you with your spirituality or religion?”
“If you have no spirituality/religion, skip this item”
[9.3% volunteered they had no such beliefs]

Then later we added a gating question:

“Do you have spiritual or religious beliefs?” (Survey 24-27)
Y/N   [If ‘yes’]   ----continue
[42.2% stated they had no such beliefs]
Principles

1. Keep all questions short and simple
   (NEVER use negative questions)

2. Use only common words
   Dale-Chall word list – 3,000 words deemed to be known
   by 80% of USA 10yr children;
   Oxford word list – most common 300 words;
   Voice of America Special English]

3. Make sure all questions are relevant
   to the respondent

4. Keep the questionnaire short
Pitfall #3

The problem

If someone indicates they do not understand a question,
what should YOU do?
When respondents indicate they do not understand a question, what should you do?

**QOLQ manual:** “You may paraphrase items and repeat them as often as necessary to ensure the respondent’s understanding of the item content”

Do you agree?
We can induced acquiescence


Repeating or paraphrasing a question is likely to introduce two types of error variance as:

1) The asked question will be different from the original

2) The rephrasing may be interpreted as an incorrect response. This puts pressure on the respondent to change their response
Methodological Pitfall #4

The assumption

A verbally administered scale easily solves the problem of illiteracy
Verbal scale administration is fraught with difficulty

Problems of communication and comprehension

- High attention required
- Cannot easily revise
- Issues of accent, inflection and speed of speech
- Must recall the response options AND recall the question
Quality of Life Questionnaire

‘What about your opportunities for dating or marriage?’

Response options:

a) ‘I am married, or have the opportunity to date anyone I choose’

b) ‘I have limited opportunities to date or marry’

c) ‘I have no opportunity to date or marry’.
Principle

The person being interviewed must understand the response options before they are asked to respond to a question that provides a number of response options.
Methodological pitfall #5

The assumption
Replacing numerical scales with smiling/frowning faces makes responding to the scales more reliable
Problem of literal interpretation

“But, when I am very sad I do not cry”
Methodological Pitfall #6

The assumption

Someone who knows the person well can respond on their behalf

[Proxy responding]

http://spiritinfusion.blogspot.com/uploaded_images/old%20couple-743330.jpg
Problem:
Such responses are based on

1) Unverified interpretations of limited information exchanges

2) Self enhancement (caregivers rate the autonomy of the people in their care as higher than the people themselves)

3) Objective information [Prejudice] (physicians rate the life quality of their patients as lower than do the patients)
Who is qualified to report on subjective wellbeing?
Who is qualified to report on subjective wellbeing?

Only the person who owns it!

Subjective wellbeing cannot be validly rated by proxy.
‘How satisfied are you with life as a whole?’

Question:
Assuming a 0 – 100 scale, how would this man rate his life?

**Group 1:** Group of health professionals (N=273, 21-59). All had experience in caring for people with muscular dystrophy.

**Group 2:** People with Duchenne Muscular Dystrophy using long-term mechanical Ventilator support (N=82, 21-59y)

**Group 3:** Health professionals responding as proxies for people with ventilator support
‘How satisfied are you with life in general?’

Strength of satisfaction

Professionals rating themselves: 88.7

People on a ventilator rating themselves: 83.1

Professionals rating people on a ventilator: 38.5

Mean: 72.7

One standard deviation

Normative Range
How to measure SWB for people who cannot respond reliably to the PWI-ID pre-testing?

We cannot, and I suspect we never will be able to make such measurement, because the problem is a cognitive barrier. If people have no abstracting capacity, they cannot respond to the PWI items.
What we can measure

1. Ensure quality of living
2. Determine choice preference
3. Obtain the opinion of other people [not proxy]
Life Satisfaction = 67.5 ± 17.7 %SM

Physical health explained 7% of life satisfaction variance