

# Quality of Life (QoL) for Post Polio Syndrome: A Needs-based Rasch-standard QoL Scale

Tennant, A.,<sup>1</sup> Quincey, A.,<sup>2</sup> Wong, S.,<sup>2</sup>  
& Young, C. A.<sup>2</sup>

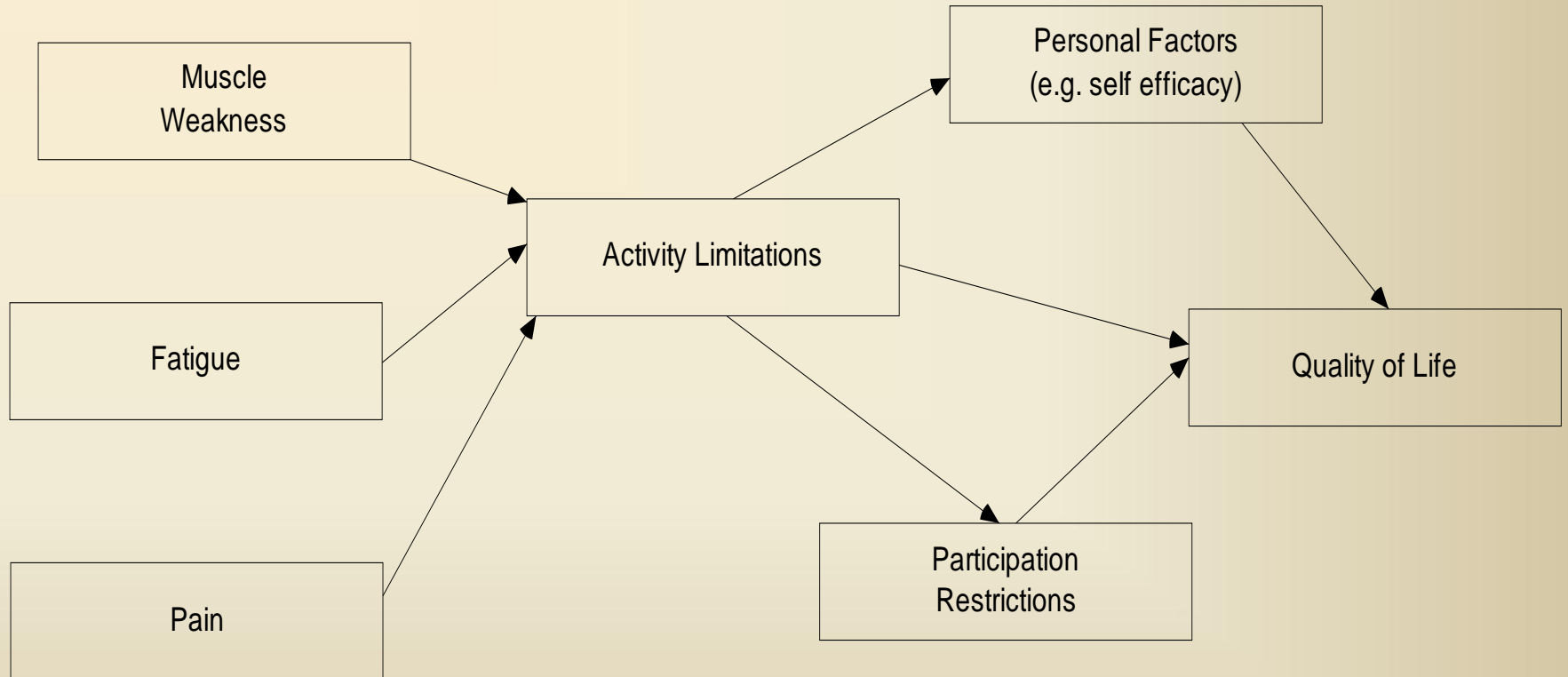
1. Department of Rehabilitation Medicine, The University of Leeds, UK.
2. The Walton Centre Liverpool, UK .

# Quality of Life

‘....an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.’

[http://www.searo.who.int/en/section1174/section1199/section1570\\_16037.htm](http://www.searo.who.int/en/section1174/section1199/section1570_16037.htm)

# WHO Biopsychosocial Model with Quality of Life



# Quality of Life Theoretical Perspectives

- Subjective Well-Being
- Life Satisfaction
- Needs-Based
- Individualistic

# Quality of Life Theoretical Model

- The Needs-Based Quality of Life model\*
- Draws on theories of human motivation\*\*
- Individuals are driven or motivated by their needs
- Thus life gains its quality from the ability and capacity to satisfy needs.

\*Hunt SM, McKenna SP. The QLDS: A scale for the measurement of quality of life in depression. Health Policy 1992; 22:307-319.

\*\* Maslow AH. Motivation and Personality. (2<sup>nd</sup> Ed). New York:Harper & Row, 1970.

# The QLDS: a scale for the measurement of quality of life in depression.

Hunt, S M. McKenna, S P.

Health Policy. 22(3):307-19, 1992 Oct.

This paper describes the development and testing of the Quality of Life in Depression Scale (QLDS).

The theoretical basis for the instrument is that life gains its quality from the ability and capacity of the individual to satisfy his or her needs.

The items included in the QLDS were derived from 30 qualitative interviews with depressed or recently recovered patients.

# Needs-Based QoL

de Jong, Z. van der Heijde D. McKenna S P. Whalley D. The reliability and construct validity of the RAQoL: a rheumatoid arthritis-specific quality of life instrument. *British Journal of Rheumatology* 1997; 36:878-83.

McKenna SP, Doward LC, Meads D, Patrick D, Tennant A.  
Summary of Needs-Based Quality of Life Instruments.  
*Value in Health* 2004; 7 (S1)

# Needs-Based QoL

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# A Needs-based QoL Scale for Post Polio Syndrome

# Recruitment Into Study

- Volunteers with Post Polio Syndrome (PPS) were recruited from across the UK. Eligible participants reported all of the following features:-
  1. Confirmed history of polio
  2. Partial or fairly complete recovery after the acute episode
  3. Period of at least 15 years with neurological and functional stability
  4. New muscle weakness in muscles previously affected or unaffected
  5. Extensive fatigue

# Stage 1: Qualitative Interviews

- 45 patients diagnosed with PPS
- Interviews were transcribed
- Items selected which were consistent with the Needs-based model

# The Qualitative Interviews

- 23/45 of those interviewed were female.
- 5 patients who were receiving Non Invasive Ventilation (NIV) for Post Polio respiratory insufficiency were included as it was thought this may influence QoL.
- Participants were located in geographical regions all over the UK to increase the diversity of the sample.

# Themes Emerging

- Need for clear self-identity
- Need to be free from Fear
- Need not to be limited by the condition
- Need for relationships with others to be unaffected
- Need to be able to cope and respond to the condition

# Statements Made by those with Post Polio

	TRUE	NOT TRUE
I feel dependent on others	<input type="radio"/>	<input type="radio"/>
I feel older than my years	<input type="radio"/>	<input type="radio"/>
My inability could affect relationships	<input type="radio"/>	<input type="radio"/>
Fatigue affects the amount I can do in a day	<input type="radio"/>	<input type="radio"/>
My social life is reduced by my condition	<input type="radio"/>	<input type="radio"/>
Sometimes people don't understand that I need help	<input type="radio"/>	<input type="radio"/>
It is difficult to join in activities with my friends and family	<input type="radio"/>	<input type="radio"/>

# Stage 2. Cognitive Debriefing

- Draft questionnaire presented to those with PPS to see if the questions could be understood.
- Was anything important missing?

# Stage 3. Postal Questionnaire

- Questionnaire pack which included some comparator measures
  - WHOQoL- Bref (WHOQoL Group. Development of the World Health Organisation WHOQOL-BREF quality of life assessment. *Psychological Medicine* 1998; 28:551-8)
  - Hospital Anxiety and Depression Scale (HADS) (Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-70.)
  - Perceived Impact Problem Profile (PIPP) (Pallant JF, Misajon R, Bennett E, Manderson L: Measuring the impact and distress of health problems from the individual's perspective: development of the Perceived Impact of Problem Profile (PIPP). *Health Qual Life Outcomes* 2006, 4(1):36.)

# Stage 4: Scale Development

- Exploratory Factor Analysis of 72 items (Are they all measuring the same thing, that is Needs-based QoL?)
- Rasch Analysis of items deemed to be measuring QoL (Do the items satisfy the strict rules for constructing proper measurement?).

# Response to Postal Questionnaire

- 284 out of 319 (89%) volunteers with PPS returned the questionnaire. The analysis used data from 272 PPS volunteers (85%)
- The PPS sample was 65% female with a mean age of 67 years (SD=8.2).

# Fatigue and Depression

- The average level of fatigue as shown by the FSS was 5.79 (SD 1.11). (Maximum 7)
- Over two-in-five (41.1%) showed at least 'possible' anxiety of the HADS, and over one-in-five (21.1%) showed 'probable' anxiety.
- Over a quarter (28.8%) showed at least 'possible' depression, and just over one-in-fourteen (7.1%) showed 'probable' depression.

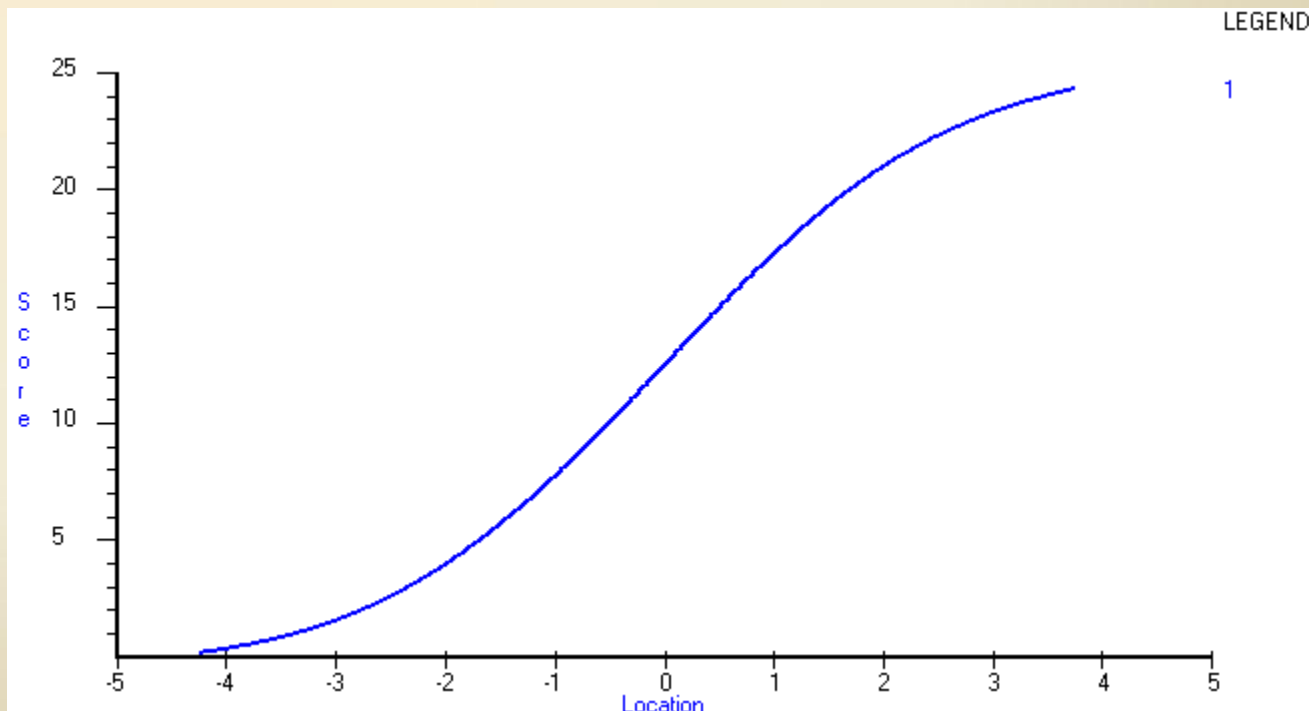
# Exploratory Factor Analysis of 72 Items

- A two factor solution (RMSEA=0.032)
- Suggested that one domain was QoL with 41 items, a second Fatigue with 31 items.
- The 41 items were taken forward to the Rasch analysis

# Fit of Data to Rasch Model

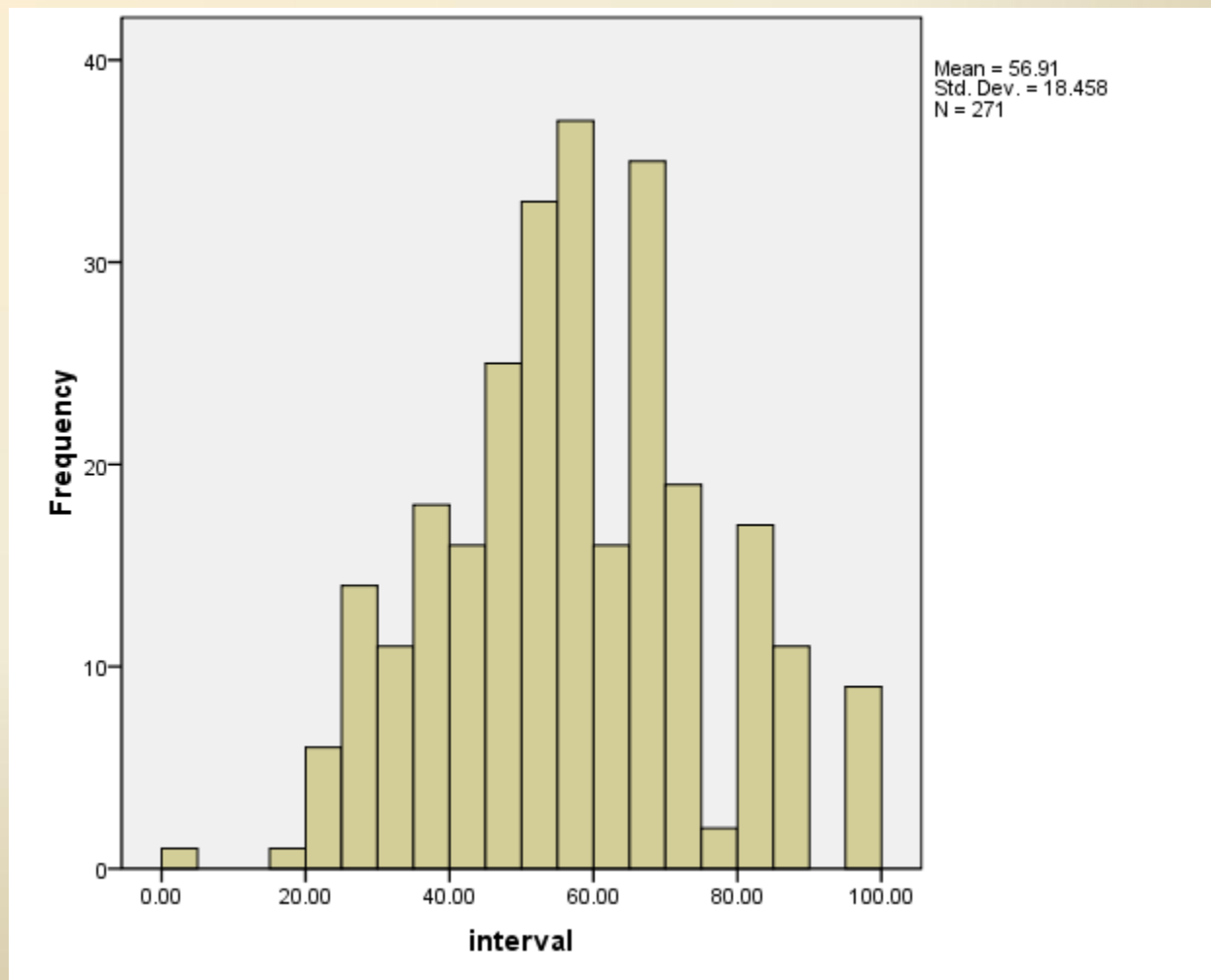
Analysis	Item Residuals		Person Residuals		Chi-Square		Reliability		Unidimensionality	
	Mean	SD	Mean	SD	Value	p	PSI	$\alpha$	% > 5%	CI
1. All 41 items	-0.423	1.496	-0.281	1.032	217.3	<0.001	0.890	0.912	13.1	10.3-15.7
1. 25 items	-0.418	1.120	-0.232	0.851	104.3	0.014	0.828	0.870	3.6	0.9-6.3
<b>Ideal Values</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>		<b>&gt;0.5*</b>	<b>&gt;0.85</b>	<b>&gt;0.85</b>	<b>&lt;5.0</b>	<b>LOWER CI &lt;5</b>

# Raw Score-Interval Scale Conversion



# Distribution of QoL Score on 0-100

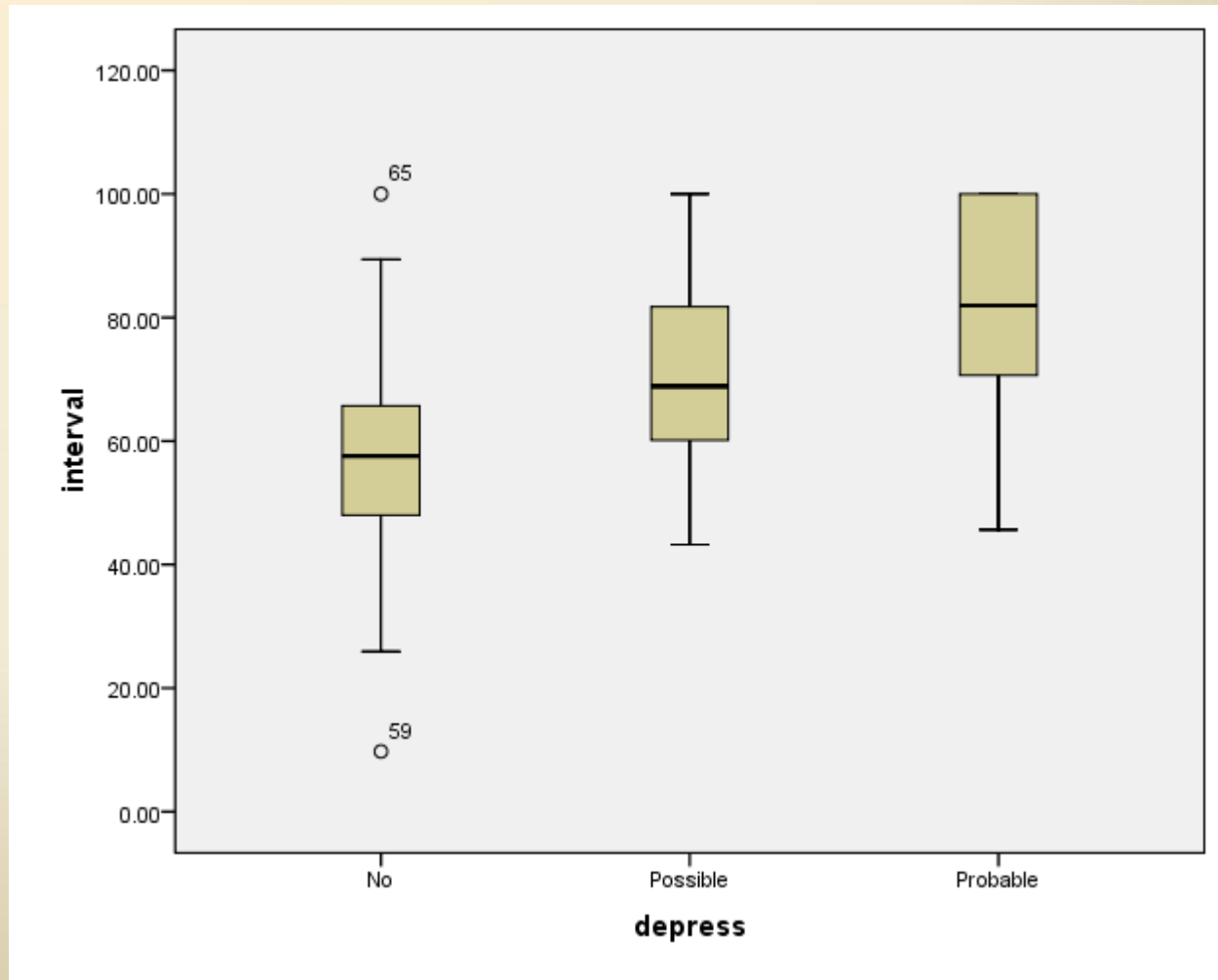
## Interval scale



# Correlations with Comparator Scales

- With WHOQoL-Bref Physical (-0.478)
- With WHOQoL-Bref Psychological (-0.524)
- With HADS –D (0.594)
- With HADS-A (0.501)
- WITH PIPP Well being (0.503)

# Association Between Depression and QoL



# Conclusions

- A 25 item self-completed scale provides a need-based QoL measure for Post Polio Syndrome.
- It has reliability consistent with individual use.
- Given fit of data to the Rasch model, the raw score (0-25) can be converted to interval scale (e.g. 0-100).
- It demonstrates expected correlations with comparator measures
- The scale is free for use in all not-for-profit and public health agencies, after a simple registration.

# With Thanks

- *We are grateful for an unrestricted grant from the British Polio Fellowship*
- *To our many research volunteers.*