Health professionals concerns about using quality of life measures

Deyo & Patrick (1988) identified 3 broad types of concern:

Conceptual or attitudinal: Clinicians views about QOL and its measurement

Methodological: Related to the selection and quality of QOL instruments.

Practical: Time and resources needed to collect QOL data

Sharing concepts about what is (and is not) quality of life......

The WHOQOL Group (1993)

15 WHOQOL Field Centres

Melbourne, Australia
Panama City, Panama
Seattle, USA
Harare, Zimbabwe
New Delhi, N. India
Madras, S. India
Bangkok, Thailand
Tokyo, Japan

St. Petersburg, Russian Fed.
Zagreb, Croatia
Barcelona, Spain
Paris, France
Tilburg, Netherlands
Bath, UK
Beer Sheva, Israel
Definition of Quality of life

An individual’s perception of their position in life, in the context of the culture and values in which they live and in relation to their goals, expectations, standards and concerns.

The WHOQOL Group (1993)

Conceptual confusion about what is quality of life

Quality of life is NOT

Standard of living
Survival
Number of symptoms or their intensity
Treatment response
Happiness (on its own)
Well-being (only part of it)

Standard of Living & Quality of Life

‘Standard of living is two TV’s, two ‘fridges, two cars & one psychiatrist.

Quality of life is one TV, one ‘fridge, one car & no psychiatrist.’

Michael Frayn
Shared assumptions of instrument developers

Self-report is the only way to assess QoL because only individuals can validly judge their QoL and judge it comprehensively. Quality of life is socially constructed. People construct QoL in domains that they consider to be important. QoL is a relativistic construct e.g. evaluation is related to best and worst possible states.

Unshared assumptions: being positive (WHOQOL Group, 1994)

Need for a holistic and balanced assessment of life - not purely problem-centred
Value to respondents from thinking positively
Value to health professionals too
Comprehensive coverage of concept.
Frame concepts positively wherever possible e.g. independence not dependence
Frame item wording in a positive way wherever possible e.g. support not isolation

Some uses of QOL information

Assessing the effectiveness and relative merits of different treatments
Health services evaluation: completeness and quality of services
Monitoring changes in policy
Improving health professional - patient communications*
Improvements to diagnosis & treatment in medical practice*

Why should health professionals use quality of life information in decision-making?

QOL information should be integrated into practice so that it adds value to patient care. It is often cheaper than a laboratory test (Mayo Proceedings, 2007). It may be used as a prognostic indicator; to provide warning of disease or recurrence e.g. breast & lung cancer (Herndon, 1999).
More reasons....

The data quality is better when patients report their own QOL than when health professionals provide proxy judgements. Some studies point to improved understandings & communications between health professionals & patients. Has potential to improve multidisciplinary working.

Why now?

We have devised patient-centred methods to develop assessments that are highly appropriate for use in patient-led care. QOL measures are sufficiently mature and high quality to justify their use in clinical practice. PROs used in 968 clinical trials published in last 2 yrs. Most phase III & IV trials collect PRO data (Sloan,2007).

Patients for Quality of Life assessment?

- Chronically ill patients with illness that is:
  - Intermittent: asthma, migraine, back pain
  - Symptomatic: some cancers, emphysema
  - Asymptomatic: hypertension, diabetes
- Avoid complications: stroke, angina
- Vulnerable groups: older adults
- Special conditions: women’s health, postsurgical

Properties of ‘good’ scales

(Butz & Cooper, 1998)

- Appropriateness
- Reliability
- Validity
- Responsive to change
- Precision*
- Interpretability*
- Acceptability*
- Feasibility*
**Stages of the WHOQOL Development.**

Concept clarification
Qualitative pilot study
Generation of a preliminary global question pool
Generation of response scales
Quantitative pilot & psychometric evaluation of the WHOQOL.

**Instructions to Focus Groups**

Facet 4: Positive Feelings
This facet examines how much a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy and enjoyment of good things in life. A person’s view of, and feelings about the future are seen as an important part of this facet. For many respondents, this facet may be regarded as synonymous with quality of life. Negative feelings are not included because they are covered elsewhere.

Example: a Buddhist monk who has attained balance and contentment.

**Levels of Questioning about Quality of Life**

Example of Sleep

**Objective Quality of Life**
e.g. EEG readings: sleep depth & patterns

**Perceived Objective Quality of Life**
How many hours do you sleep?

**Self-Report Subjective Quality of Life**
How refreshing is your sleep?

**Changes to the WHOQOL**

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Centres</td>
<td>10</td>
<td>15</td>
<td>15</td>
<td>30+</td>
</tr>
<tr>
<td>Methods</td>
<td>Qualitative</td>
<td>Quantitative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Versions</td>
<td>Pilot</td>
<td>100</td>
<td>BREF</td>
<td></td>
</tr>
<tr>
<td>Domains</td>
<td>6</td>
<td>6</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Facets</td>
<td>134</td>
<td>33</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Items</td>
<td>2,500</td>
<td>235</td>
<td>100</td>
<td>26</td>
</tr>
</tbody>
</table>
WHOQOL-Bref Global Sample
(N=11,830)
Mean age 45 years (SD=16) 12-97 years *
Women 53%; Men 47%*
Well 53%; Sick 47%. 28 identifiable physical or mental health conditions in 14 ICD-10 categories.
Most prevalent conditions: cancer 17%; diabetes 11%; depression 11%; cardiovascular dis.11%.
Married/living as married 60%, single 25%
Education:
36% primary, 40% secondary, 24% tertiary
* Significant sex & age differences across centres

Internal Consistency Reliability
Cronbach’s alpha (α > .70)

Overall α for Domains & number of items
Range across countries & number < 0.7
Physical (7) .82 .55 - .87 (2)
Psychological (6) .81 .65 - .89 (1)
Social (3) .68 .51 - .77 (16)
Environment (8) .80 .65 - .87 (3)

Domains I and II of the WHOQOL
Physical Health I
Pain & discomfort
Energy & fatigue
Sleep & rest
Mobility*
Activities of daily living*
Dependence on medication & treatment*
Working capacity*
Psychological II
Positive feelings
Thinking, learning, memory & concentration
Self-esteem
Body image & appearance
Negative feelings
Spirituality, religion & personal beliefs*

Domains III and IV of the WHOQOL
Social Relationships III
Personal relationships
Practical social support
Sex-life
Environment IV
Physical safety & security
Home environment
Financial resources
Availability & quality of health & social care
Acquiring new information & skills
Opportunities for recreation & leisure
Physical environments
Transport
Testing discriminant validity
(n = no. of countries not significant)

<table>
<thead>
<tr>
<th>Sick vs Well (means)</th>
<th>t</th>
<th>p</th>
<th>n*</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.1 15.4</td>
<td>39.2</td>
<td>.01</td>
<td>5</td>
</tr>
<tr>
<td>13.7 14.8</td>
<td>19.9</td>
<td>.01</td>
<td>5</td>
</tr>
<tr>
<td>14.0 14.8</td>
<td>13.0</td>
<td>.01</td>
<td>6</td>
</tr>
<tr>
<td>13.8 14.1</td>
<td>7.6</td>
<td>.01</td>
<td>10</td>
</tr>
</tbody>
</table>

* especially Italy, Israel, Madras, Norway, Spain.

Construct Validity:
range of item-domain correlations

Good item-domain correlations (r)

- Physical: .48 (pain) to .70 (activities)
- Psychological: .50 (neg. feels) to .65 (spiritual)
- Social: .45 (sex) to .57 (personal rel’ns)
- Environment: .47 (leisure) to .56 (finance)

Domain intercorrelation range: .46 to .67

QOL around the world in 1999
(WHOQOL-BREF) (n=11,830)

How much do doctors use quality of life information in primary care?

Suzanne Skevington
Rachel Day
Alison Chisholm
Paul Trueman

Quality of Life Research (2005) on line
Advantages of using generic measures in general practice.

GPs would not be required to select a different disease-specific scale every time they need to make a QOL assessment.

Enables comparisons between many different diagnostic groups, as well as within a condition.

Where generic measures have been designed for use with healthy people and norms are available, this provides baseline information for that culture.

Aims

To assess the current usage of QOL information in primary care: reasons, barriers to use, ideas for overcoming these barriers.

To apply a model that would enable identification of levels of knowledge and interest in QOL.

Rationale:

This information could indicate the likelihood of a GP using this information routinely.

It could also assist in the design of appropriate interventions.

Trans-Theoretical Model of Behaviour Change (TTM) (Prochaska & Di Clemente et al 1992)

Five Stages:

Stage 1. Precontemplation: Unaware or unconcerned about QOL. ‘I do not intend to use QOL information’

Stage 2. Contemplation: Aware of QOL issues but lack of motivation to use – barriers?

‘I have thought about it but am unlikely to use QOL information in the future’

Stage 3. Planning: Positive attitude towards QOL, higher motivation to use, more knowledge.

‘I plan to use QOL information’

Stage 4. Action: Have started to use QOL information confidently & competently but not regularly.

‘I have used QOL information but not routinely’

Stage 5. Maintenance: Sees the value of using QOL information regularly.

May seek ways of improving practice so needs support & feedback.

‘I assess QOL regularly & would like to know more (about it)’

More stages…
Sample
Representative cross-section of 800 GPs randomly selected from UK Medical Register (1999)
10 ‘old’ Health Authority regions
Inclusions: MRCGP + employed & practicing
Postal survey: 38% response rate

Distribution of GP’s in survey

Graph of respondents by region

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Channel Islands</td>
<td>20</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>10</td>
</tr>
<tr>
<td>Wales</td>
<td>0</td>
</tr>
<tr>
<td>Scotland</td>
<td>4</td>
</tr>
<tr>
<td>North West</td>
<td>12</td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>11</td>
</tr>
<tr>
<td>West Midlands</td>
<td>11</td>
</tr>
<tr>
<td>Anglia &amp; Oxford</td>
<td>14</td>
</tr>
<tr>
<td>North Thames</td>
<td>7</td>
</tr>
<tr>
<td>South Thames</td>
<td>13</td>
</tr>
<tr>
<td>South West</td>
<td>18</td>
</tr>
</tbody>
</table>

Graph of GP’s importance rating of QOL

<table>
<thead>
<tr>
<th>Rating of importance</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all important</td>
<td>29</td>
</tr>
<tr>
<td>1</td>
<td>31</td>
</tr>
<tr>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Very important</td>
<td>38</td>
</tr>
</tbody>
</table>

Do you use QOL information? (N=272)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 Pre-contemplation</td>
<td>22%</td>
</tr>
<tr>
<td>Stage 2 Contemplation</td>
<td>18%</td>
</tr>
<tr>
<td>Stage 3 Planning</td>
<td>7%</td>
</tr>
<tr>
<td>Stage 4 Action</td>
<td>36%</td>
</tr>
<tr>
<td>Stage 5 Maintenance</td>
<td>15%</td>
</tr>
<tr>
<td>Stage 0 Immotives ‘Do not intend to use’</td>
<td>2%</td>
</tr>
</tbody>
</table>

Have you ever used QOL information?
Yes: 58%   No: 42%
Why is QOL not used in daily practice?

Do not understand how QoL information would be used 51%
Do not fully understand the evidence 19%
Do not know what QoL is 8%
No access to QoL information 7%
No evidence available 5%
No resources or time 4%
Have not seen any benefits from using QoL information 4%

Which dimensions are most useful?

Domains of QOL % agreement
Psychological 88%
Physical health 87%
Social relationships 78%
Independence 72%
Environment 57%
Spirituality 35%

Mean ranking of disease groups and disorders for QoL assessment (1= high)

<table>
<thead>
<tr>
<th>% Disorders</th>
<th>Mean</th>
<th>% Disorders</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>60 Cancers</td>
<td>2.3</td>
<td>22 Dermatology</td>
<td>5.9</td>
</tr>
<tr>
<td>55 Cardiovascular</td>
<td>2.8</td>
<td>23 Accidents</td>
<td>6.0</td>
</tr>
<tr>
<td>52 Mental</td>
<td>2.9</td>
<td>22 Gastrointestinal</td>
<td>6.0</td>
</tr>
<tr>
<td>54 Respiratory</td>
<td>3.6</td>
<td>21 Substance use</td>
<td>6.2</td>
</tr>
<tr>
<td>39 Nervous/senses</td>
<td>4.5</td>
<td>19 Genitourinary</td>
<td>6.2</td>
</tr>
<tr>
<td>37 Musculo-skeletal</td>
<td>4.6</td>
<td>18 Endocrine</td>
<td>6.5</td>
</tr>
<tr>
<td>29 Pregnancy &amp; Birth</td>
<td>5.0</td>
<td>16 Blood/Immune</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 Infections</td>
<td>7.5</td>
</tr>
</tbody>
</table>

How do GPs measure Quality of Life?

<table>
<thead>
<tr>
<th>Method</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal recording in notes</td>
<td>123</td>
<td>59</td>
</tr>
<tr>
<td>General discussion; not recorded</td>
<td>57</td>
<td>28</td>
</tr>
<tr>
<td>Formal standardised questionnaires</td>
<td>23</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>
### Knowledge of QOL measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Anxiety &amp; Depression Scale</td>
<td>105</td>
<td>38</td>
</tr>
<tr>
<td>Short Form-36</td>
<td>39</td>
<td>14</td>
</tr>
<tr>
<td>WHOQOL</td>
<td>33</td>
<td>12</td>
</tr>
<tr>
<td>Nottingham Health Profile</td>
<td>24</td>
<td>9</td>
</tr>
<tr>
<td>Sickness Impact Profile</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>Short Form-12</td>
<td>18</td>
<td>6</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Quality of Well-Being scale</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Health Utilities Index</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

### Difficulties with using QOL assessment in General Practice

<table>
<thead>
<tr>
<th>Theme</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time shortage - general</td>
<td>66</td>
<td>43</td>
</tr>
<tr>
<td>Access to recent information</td>
<td>28</td>
<td>18</td>
</tr>
<tr>
<td>Concerns about effective use</td>
<td>25</td>
<td>16</td>
</tr>
<tr>
<td>A burden; little/no interest</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Time to complete scale</td>
<td>18</td>
<td>12</td>
</tr>
<tr>
<td>Validation not available</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Difficulty with formal use</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Lengthens consultation</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Time to collect &amp; record data</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Further skills &amp; training needed</td>
<td>9</td>
<td>6</td>
</tr>
</tbody>
</table>

### It takes too long...??

Time taken to administer in randomised studies of patients in cancer care:

- Velikova et al (2001)
  - Intervention - feedback on QOL: 12.8 mins
  - Attention control - QOL no feedback: 13.6
  - Control group - no QOL in clinic: 12.8

- Detmar & Aaronson (2002)
  - Intervention: 19.8 mins
  - Control: 20.3 mins

### Views about how QOL information can be used

<table>
<thead>
<tr>
<th>Uses of QOL</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage treatment of patients</td>
<td>203</td>
<td>73</td>
</tr>
<tr>
<td>Improve satisfaction &amp; adherence</td>
<td>160</td>
<td>57</td>
</tr>
<tr>
<td>Monitor effectiveness of treatment</td>
<td>142</td>
<td>51</td>
</tr>
<tr>
<td>Improve communication with patients</td>
<td>129</td>
<td>46</td>
</tr>
<tr>
<td>Manage resources</td>
<td>87</td>
<td>31</td>
</tr>
<tr>
<td>Assess side-effects</td>
<td>84</td>
<td>30</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>77</td>
<td>28</td>
</tr>
<tr>
<td>Audit</td>
<td>77</td>
<td>28</td>
</tr>
<tr>
<td>Epidemiological studies</td>
<td>48</td>
<td>17</td>
</tr>
<tr>
<td>To aid diagnosis</td>
<td>43</td>
<td>15</td>
</tr>
<tr>
<td>Screening</td>
<td>25</td>
<td>9</td>
</tr>
</tbody>
</table>
How to make QOL information more accessible & relevant to general practice

Themes   N   %
Increase access to publicat’ns, scales, evidence 47   20
Knowing how and why to use QOL 46   20
Use scales: simplify & shorten them 43   18
IT: internet & computers 32   14
Increase time with patients 16   7
Designated health staff to assess 12   5
Patient-completed questionnaires 12   5
Don’t know 12   5

Exploratory investigation of using QOL information in primary care

A CD-ROM of WHOQOL-Bref.
Short form of 26 items; fast completion.
Accommodates data and compares records for up to 4 occasions for each person.
Coloured printout of scored profile of results for patient.
GPs can review results electronically.*

Procedure

Three GPs: urban, suburban, rural locations
All male
168 patients completed the WHOQOL-Bref CD-ROM version using a ‘think aloud’ technique.
Answered questions about the package, presentation, questionnaire, results etc
After the consultation, patients & doctors asked about the use of the questionnaire.
Questions investigated using cognitive interviewing, questionnaires & debriefing methods

Is it possible to develop a package that is attractive and acceptable to doctors & patients?
Would patients be spontaneously willing to complete the package before the consultation?
Would patients from a wide range of adults age-groups & socio-economic backgrounds be able to use the software?

Is it possible to develop a package that is attractive and acceptable to doctors & patients?
Would patients find it a burden or like it?
Would they be willing to repeat it?
Would they want to show their printout to a doctor? Would they actually show it?
Would doctors inspect the profile?
How would they interpret it? How would they use it?

Continence Specialists use of Quality of Life information in Routine Practice: a national survey of practitioners.

K. Haywood, A. Garratt, S. Carrivick, J. Mangnall, S. Skevington

Summary

Cross-sectional national postal survey of 624 practising continence specialists in UK: mixed methods questionnaire 49% response rate (n=299)

Findings
Eighty % routinely assessed QOL:
- 54 % were aware of standardised questionnaires
- 41% used structured questions: 26% single items; 19% locally developed questionnaires.
- 22% used standardised patient-completed questionnaires

Conclusion
Wide variation in practice although QOL information is valued highly
Use in all health care settings
(Nurbai & Skevington 2001)

Promotes or facilitates multi-agency and multidisciplinary working
Better communications between providers of health care
Better continuity of care
Needs support from professional bodies and voluntary organisations

Practice nurses on advantages
(Nurbai & Skevington 2001)

Benefits to patients:
– faster recovery
– receiving better service
– patient satisfaction
Cost-effectiveness:
– less medication used
– fewer visits to surgeries
Evidence-based practice or ‘best practice’

Issues still to be addressed
Time & Resources: nurses, admin staff, consultation, money, paperwork, extra staff.
Patient choice
Professional attitudes: resistance from GPs
Patient honesty issues
Professional skills differences
IT limitations

A way forward??
Chose a patient group suitable for QoL assessment
Use an electronic form of assessment for speed and ease.
Try it out with several contrasting patients.
Work out how to combine assessment with other tasks
– Which tasks would be suitable?
– When would be the best time to do it?
Do it regularly to make it into a habit
If necessary, reorganise your practice environment.
Focus on the successes and talk to other enthusiasts.
More information on the WHOQOL & user registration.

www.bath.ac.uk/whoqol