

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 QOL collect 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)

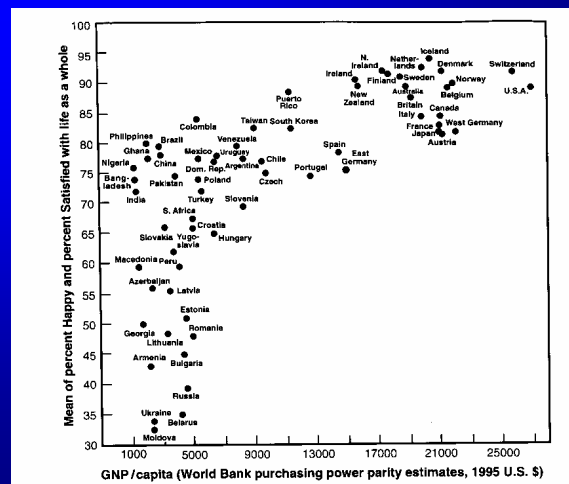


Standard of Living & Quality of Life

‘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** eg. 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

(Fitzpatrick et al,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

<u>Time</u>	<u>1991/2</u>	<u>1993/4</u>	<u>1995/7</u>	<u>1998/9</u>
Centres	10	15	15	30+
Methods	Qualitative	Quantitative.....		
Versions		Pilot	100	BREF
Domains		6	6	4
Facets	134	33	25	25
Items	2,500	235	100	26



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 ($\alpha > .70$)

Overall α for Domains & Range across countries
number of items & 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*



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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



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Testing discriminant validity

(n = no. of countries not significant)

Sick vs Well (means)	t	p	n*
13.1 15.4	39.2	.01	5
13.7 14.8	19.9	.01	5
14.0 14.8	13.0	.01	6
13.8 14.1	7.6	.01	10

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



Construct Validity:

range of item-domain correlations

Good item-domain correlations (r)

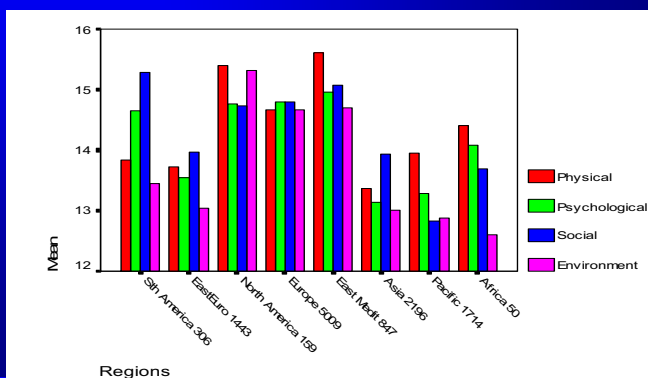
Physical: .48 (pain) to .70 (activities)
 Psychological: .50 (neg. feels) to .65 (spiritual)
 Social: .45 (sex) to .57 (personal rel'ns)
 Environment: .47 (leisure) to .56 (finance)

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. 'Immotives' slightly aware but resistant.

'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'



More stages...

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)'



Sample

Representative cross-section of 800 GPs randomly selected from UK Medical Register (1999)

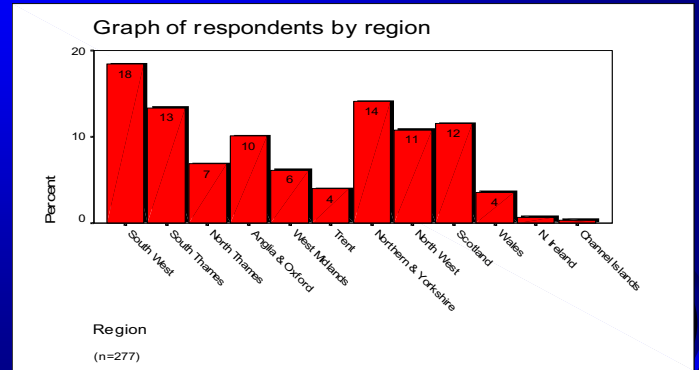
10 'old' Health Authority regions

Inclusions: MRCGP + employed & practicing

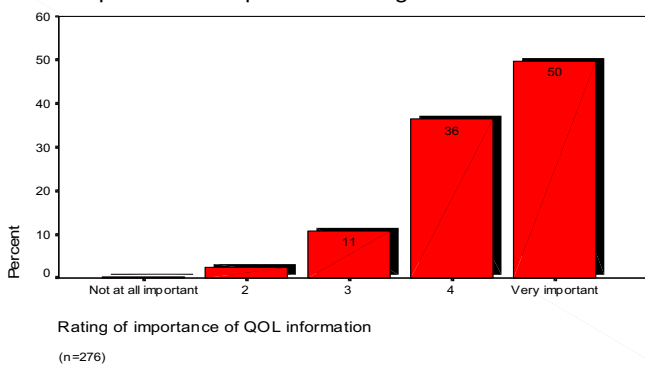
Postal survey: 38% response rate



Distribution of GP's in survey



Graph of GP's importance rating of QOL



Do you use QOL information? (N=272)

Stage 1	Pre-contemplation	22%
Stage 2	Contemplation	18%
Stage 3	Planning	7%
Stage 4	Action	36%
Stage 5	Maintenance	15%
Stage 0	Immotives 'Do not intend to use'	2%

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)

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



How do GPs measure Quality of Life?

Method	N	%
Informal recording in notes	123	59
General discussion; not recorded	57	28
Formal standardised questionnaires	23	11
Other	5	2



Knowledge of QOL measures

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



Difficulties with using QOL assessment in General Practice

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



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

Uses of QOL	N	%
Manage treatment of patients	203	73
Improve satisfaction & adherence	160	57
Monitor effectiveness of treatment	142	51
Improve communication with patients	129	46
Manage resources	87	31
Assess side-effects	84	30
Clinical trials	77	28
Audit	77	28
Epidemiological studies	48	17
To aid diagnosis	43	15
Screening	25	9



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



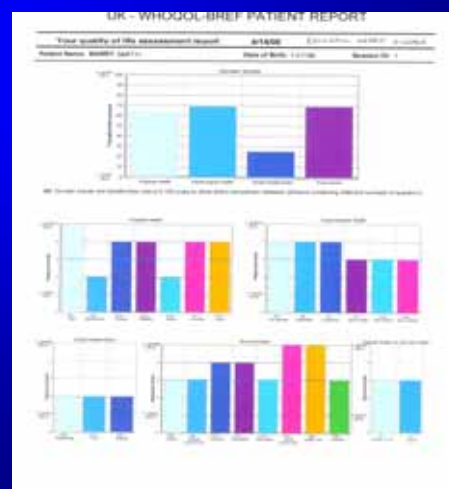
Exploratory investigation of using QOL information in primary care

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?



Questions investigated using cognitive interviewing, questionnaires & debriefing methods

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