Models and definitions of quality of life

PoCoG Quality of Life Webinar
20th August 2015

Dan Costa

(we will commence at 5 past the hour)
“Does [insert intervention] improve quality of life?”

What does this mean?
PART I
How is quality of life defined?
Where to look

1. Books

2. Research articles (empirical and theoretical)

3. Models

4. Health organisations
1. Books
“Quality of life (QoL) is an ill-defined term... most people, in the Western world at least, are familiar with the expression ‘quality of life’ and have an intuitive understanding of what it comprises.”
“Concepts of health often lack clarity... The term ‘quality of life’ also has many meanings.”
“a vague and ethereal entity, something that many people talk about, but which nobody clearly knows what to do about.”
“QOL in the Benthamite tradition is essentially contentment, whereas QOL in the Aristotelian sense in a meaningful and fulfilling life.”
2. Research articles
(empirical and theoretical)
“a kind of umbrella under which are placed many different indexes dealing with whatever the user wants to focus on.”

but seriously...

“Quality of life in clinical medicine represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient.”

“HRQOL refers to the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment.”

“HRQOL is a multidimensional construct encompassing perceptions of both positive and negative aspects of dimensions, such as physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment.”

“...the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient.”

“...the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment.”

“...a multidimensional construct encompassing perceptions of both positive and negative aspects of dimensions, such as physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment.”
3. Models
“The concept of quality of life is distinct from health, though related to it.”

“Economic, political, cultural, and spiritual factors may affect overall quality of life, but are generally not considered to fall under the purview of physicians and health care systems.”

“Health status and HRQL can refer to different concepts, but in this article we use the terms interchangeably.”
Elements vs. determinants of quality of life


So what are the elements and what are the determinants?
It depends on the definition.


3. MODELS
“Both the multitude and persons of refinement... conceive “the good life” or “doing well” to be the same thing as “being happy”. But what constitutes happiness is a matter of dispute... Some say one thing and some say another, indeed very often the same man says different things at different times: when he falls sick he thinks health is happiness, when he is poor, wealth.”

Aristotle, *Nichomachean Ethics*
4. Health organisations
“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. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”

4. HEALTH ORGANISATIONS
“HRQL is a multidomain concept that represents the patient’s general perception of the effect of illness and treatment on physical, psychological, and social aspects of life.”

“A PRO [patient-reported outcome] is any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.”
Other thoughts

Quality of life vs. unmet needs

HRQoL questionnaires: perceived direct impact of illness and its treatment.

Needs questionnaires: extent to which consequent needs for supportive care are currently met.

Conceptually and empirically similar?

Working definition

Quality of life:
what quality of life instruments measure
PART II
How is quality of life assessed?
Method of assessment

1. Descriptive questionnaires
2. Single item
3. Utility instruments
1. Descriptive questionnaires
<table>
<thead>
<tr>
<th>1. I have a lack of energy</th>
<th>15. I feel sad</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. I have nausea</td>
<td>16. I am satisfied with how I am coping with my illness</td>
</tr>
<tr>
<td>3. Because of my physical condition, I have trouble meeting the needs of my family</td>
<td>17. I am losing hope in the fight against my illness</td>
</tr>
<tr>
<td>4. I have pain</td>
<td>18. I feel nervous</td>
</tr>
<tr>
<td>5. I am bothered by side effects of treatment</td>
<td>19. I worry about dying</td>
</tr>
<tr>
<td>6. I feel ill</td>
<td>20. I worry that my condition will get worse</td>
</tr>
<tr>
<td>7. I am forced to spend time in bed</td>
<td>21. I am able to work (include work at home)</td>
</tr>
<tr>
<td>8. I feel close to my friends</td>
<td>22. My work (include work at home) is fulfilling</td>
</tr>
<tr>
<td>9. I get emotional support from my family</td>
<td>23. I am able to enjoy my life</td>
</tr>
<tr>
<td>10. I get support from my friends</td>
<td>24. I have accepted my illness</td>
</tr>
<tr>
<td>11. My family has accepted my illness</td>
<td>25. I am sleeping well</td>
</tr>
<tr>
<td>12. I am satisfied with family communication about my illness</td>
<td>26. I am enjoying the things I usually do for fun</td>
</tr>
<tr>
<td>13. I feel close to my partner (or the person who is my main support)</td>
<td>27. I am content with the quality of my life right now</td>
</tr>
<tr>
<td>14. I am satisfied with my sex life</td>
<td></td>
</tr>
</tbody>
</table>
1. DESCRIPTIVE QUESTIONNAIRES
Reflective or formative?

Reflective indicators comprise a scale

Formative (or, more specifically, causal or composite) indicators comprise an index

Elements or determinants?

1. DESCRIPTIVE QUESTIONNAIRES
2. Single item
How would you rate your overall quality of life?
Advantages

Easy for respondents to answer

Low burden

Does not (explicitly) confound elements and determinants
How do single items perform compared to multi-item scales?

Quite nicely

High test-retest reliability
Moderate-high responsiveness

Problems

Interpretation and measurement error

What are respondents thinking when they answer the question?

2. SINGLE ITEM
Problems

“Even with haemorrhoids I think my quality of life is pretty good.”

“That could be interpreted broadly to include everything or it could relate only to the cancer. Seeing as everything else I’ve said is related to the cancer I should be consistent and relate this to the cancer.”

“My life is really, really good. Except I’m renovating...”
3. Utility instruments
Weighted by preferences

i.e.,
Descriptive instruments ask “how severe” or “how often”?

Utility instruments do the same but apply a preference weighting

3. UTILITY INSTRUMENTS
Quantity vs. quality

Quantity of life

Quality of life

Survival time

Quality of life

Treatment 1

10 years

30%

0.3

Treatment 2

5 years

70%

0.35

3. UTILITY INSTRUMENTS
Multi-attribute utility instruments

Administer a small number of items (like a descriptive instrument) to patients in a clinical trial

The items have previously been valued by a large sample so that each item has a utility weight

General population usually provides valuations

3. UTILITY INSTRUMENTS
Health state = particular combination of levels

After valuation, each item level gets a utility decrement weight

3. UTILITY INSTRUMENTS
## EQ-5D

<table>
<thead>
<tr>
<th></th>
<th>Mobility</th>
<th>Self-care</th>
<th>Usual activities</th>
<th>Pain/discomfort</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>0.069</td>
<td>0.104</td>
<td>0.036</td>
<td>0.123</td>
<td>0.071</td>
</tr>
<tr>
<td>3</td>
<td>0.314</td>
<td>0.214</td>
<td>0.094</td>
<td>0.386</td>
<td>0.236</td>
</tr>
</tbody>
</table>

$3^5 = 243$ health states

Quality of life = aggregate of effects

Are these items sensitive enough?
Problem

What items go in? Who decides and using what criteria?

Implicit definition of quality of life:
“patient perception of the effects of illness and treatment as modified by various factors chosen by a specific research team and valued by a large number of other people, most of whom have not experienced the illness.”

3. UTILITY INSTRUMENTS
What about an assessment of the effects of illness and treatment weighted by what’s important to the patient?

Ask the patient to list what is important to them, then assign weight, then aggregate?

OR...

“How do we assess this?

“the value assigned to duration of life as modified by the impairment, functional states, perception and social opportunities that are influenced by disease, injury, treatment, or policy”

Health Status and Health Policy
Allocating Resources to Health Care
Donald L. Patrick
Penrifer Erickson
How would you rate your overall quality of life?
What value does the term “quality of life” have?

As an outcome of a clinical trial?

As an item in a questionnaire?

As an umbrella term for patient-reported outcome measures?

As a name for a field of research?