The EORTC QLQ-SWB36 spiritual wellbeing measure for palliative care patients with cancer: development to date and findings from UK pilot-testing

School of Health Sciences and Social Care
Health Studies and Community Health Division
Seminar Series 2010-11
1 December 2010

Bella Vivat
bella.vivat@brunel.ac.uk
Bella Vivat, Health Sciences and Social Care, Brunel University
Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, UK

France: Anne Brédart, Psycho-Oncology Unit, Institut Curie, Paris

Germany: Susanne Singer, Medical Psychology & Sociology, University of Leipzig

Iceland: Valgerður Sigurðadóttir, Guðlaug H. Ásgeirsdóttir, Palliative Care Unit, National University Hospital, Reykjavik

Italy: Fabio Efficace, Health Outcomes Research Unit, GIMEMA: Italian Group for Adult Hematologic Diseases, Rome; Anna Costantini, Psychooncology Unit, Sant'Andrea Hospital, Sapienza University of Rome, Rome

Japan: Kunihihko Kobayashi, Respiratory Medicine, Saitama International Medical Center, Hidaka-city, Saitama

Spain: Juan I. Arraras, Oncology, Hospital de Navarra, Pamplona, Navarra
Some background

Late 1980s: EORTC QLQ-C30 – the “core questionnaire”

Modular system


Minimum 3 languages and countries (Anglo-Saxon, Northern European, Southern European)

http://groups.eortc.be/qol/
Definitions and key theoretical points

SPIRITUAL WELLBEING is wellbeing related to spirituality, with 3 dimensions:
- personal relationships with self and others
- existential
- religious and/or spiritual beliefs and/or practices

Assessment/measurement – intervention

Spiritual care:
“being there”, “presence”, listening, attending, accompanying

Phases I and II: 2001-2

Literature review → 84 issues

Personal relationships with self and others (P): 29 issues
Existential (Q): 24 issues
Religious and/or spiritual beliefs and/or practices (R): 31 issues

Interviews with patients (n=22) & health/social care professionals (n=22)

Austria, Belgium, Croatia, Iceland, Italy, the Netherlands, UK

- Relevance (not at all – very much)
- Importance (choose 25-30 issues, at least 5 from each of P, Q and R)
- Additional issues
- Similarities between issues

Ranking score: 2 x include + very relevant

Phases I and II: 2001-2

23 issues deleted:
- 13 lower ranked (less relevant/important)
- 10 high correlations with included issues

2 issues amended and subdivided -> 4 items
6 new issues added

69 items

QLQ-SWB69

Report to EORTC Quality of Life Group Module Development Committee (MDC) & peer-review: asked to further reduce length of measure
Phase IIIa: pilot pre-testing of QLQ-SWB69: 2003-4

Patient interviews (n=17) → Iceland, Italy, UK

35 items deleted
3 items amended:
- 2 rephrased
- 1 split into 2
3 new items added

Deletions:
- low prevalence (<25%)
- missing data
- correlations
- translation difficulties (3 items)
  (translation questionnaire in 7 European countries)

38 items

QLQ-SWB38

Report to MDC & peer-review
Phase IIIb: pre-testing of QLQ-SWB38: 2006-10

Patient interviews (n=113)

France, Germany, Iceland, Italy, Japan, Spain, UK

2 items deleted
7 items amended:
- 3 combined to 1
- 2 combined to 1
- 2 re-constructed -> 4 items
1 new item added

36 items

QLQ-SWB36
Report/paper under review
Structure of EORTC QLQ-SWB36

35 statements
  e.g. I have felt at peace with myself

Response scale
  Not at all (1) – a little (2) – quite a bit (3) – very much (4)
## EORTC QLQ-SWB36

The 1st page of this measure focuses on your thoughts and feelings **during the past week**. Please respond to all of the statements yourself by circling the number that best applies to you. There are no “right” or “wrong” answers. The information that you provide will remain strictly confidential.

<table>
<thead>
<tr>
<th>During the past week ......</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I have felt able to deal with problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2 I have felt at peace with myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3 I have felt able to forgive myself for things I have done</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4 I have felt troubled</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5 I have worried about the future of people who are important to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6 I have felt lonely</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7 I have felt able to share thoughts about life with people who are close to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8 I have felt loved by those who are important to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Structure of EORTC QLQ-SWB36

Final item (no. 36) (no. 38 in pilot-tested QLQ-SWB38)

How would you rate your overall spiritual wellbeing?

Very poor (1) – Excellent (7)
Can't answer/Don't know (0)
Comprehensibility and acceptability

Help:
3 with understanding (1 German, 2 Japanese)
9 practical (e.g. reading/sight difficulties)
43 company/discussion during/after (UK, Spain, Iceland, France)

difficult – annoying – confusing – upsetting – intrusive – irrelevant

4 items no comments; 6 items only 1 comment.
For most items at least 1 respondent commented that it was difficult.
Most comments for items 3, 25, 33, 34, 37 (max. 8 comments)

General comments
"I think this is quite a good questionnaire; it asks the right sort of questions... about the right sort of things."
Assessment/measurement – intervention

“The questions were only difficult in as much as they meant having to consciously think “What do I think about this?” “What are my thoughts?” Having to consciously think about things which are anyway at the back of my mind. Not at all intrusive, in fact a bit contemplative, and that’s a good thing.”

“Being referred here [to the hospice] is the best thing that’s ever happened to me; the socialising and the support. [Tearful] Thank you for listening to me.”
Assessment/measurement – intervention

Transcript 08 – Dec 2006 – Jim. Scottish, active Roman Catholic
Age 51, living with wife and one adult daughter
Lung cancer, no secondaries, prognosis 6-12 months

BV: so... on the first page... were any of these questions difficult for you?
Jim: no, none of them were difficult, I think I've come to terms with it now, with having it
BV: ah hah
Jim: I think I've kind of managed that, I'm feeling fairly positive now, compared with when I first...
BV: when were you diagnosed?
Jim: last summer
BV: last summer, mmm, mmm
Jim: aye, so I mean... in that respect I felt it quite difficult
BV: ah hah
Jim: in the start obviously I was...
BV: mmm
Jim: bubbling, crying... like anybody, you were greeting like, you know?
BV: mmm
Jim: which is fine... err... I think that's kind of a normal way to go
BV: mmm
Jim: but... since that... after two or three weeks you were trying not to think....
BV: mmm
Jim: well, when I say trying, I can't ever not think of it, it's in the back of your mind, it's part of my mind now, it's always going to be there, it'll never leave my mind now [...] it is there now, it's part of my life, it's part of me
BV: mmm
Jim: but I've accepted it, my family's accepted it
BV: mmm
Jim: err... and I felt, as well, the questionnaire, it goes on and asks how... friends and family and all of that kind of, how they feel about it, how they've accepted it, as well, so...
BV: mmm
Jim: obviously we try not to talk about it, as well, but there is times when I do have wee downers
BV: of course
Jim: and I just kind of feel about it, you know, why me?
BV: mmm
Jim: and again there’s a question there, in the questionnaire
BV: yes, there’s a question there, isn’t there, about it being unfair?
Jim: yes, feeling that it’s unfair
BV: yes, I have felt that it’s unfair
Jim: and I did feel that it was unfair as well, because I was a worker
BV: mmm
Jim: from when I left school I was never out of work, never at the doctor
[...]
Field-testing of QLQ-SWB36 to begin in 2011

Collaborators
continuing:  UK: B Vivat, T Young (Mount Vernon Cancer Centre)
           Japan
           Iceland
           France, Italy, Spain

new:        Switzerland (German-speaking), Poland
           Mexico, Chile
           Australia
           New Zealand
           Nepal

possible:   India
           Canada
           US