

**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  
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## Some background

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

Aronson NK, Ahmedzai S, Bergman B, et al., for the European Organization for Research and Treatment of Cancer (1993). The EORTC QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *JNCI*, 85: 365-376.

### **Modular system**

**Module Development Committee** – Guidelines (3<sup>rd</sup> edition, 2002)

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

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



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

difficult – annoying – confusing –  
upsetting – intrusive – irrelevant

Comments on problem items

Help needed?

Time scales?

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)

Your initials:

Date:

Study number:

### 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.

	During the past week .....	Not at all	A little	Quite a bit	Very much
1	I have felt able to deal with problems	1	2	3	4
2	I have felt at peace with myself	1	2	3	4
3	I have felt able to forgive myself for things I have done	1	2	3	4
4	I have felt troubled	1	2	3	4
5	I have worried about the future of people who are important to me	1	2	3	4
6	I have felt lonely	1	2	3	4
7	I have felt able to share thoughts about life with people who are close to me	1	2	3	4
8	I have felt loved by those who are important to me	1	2	3	4

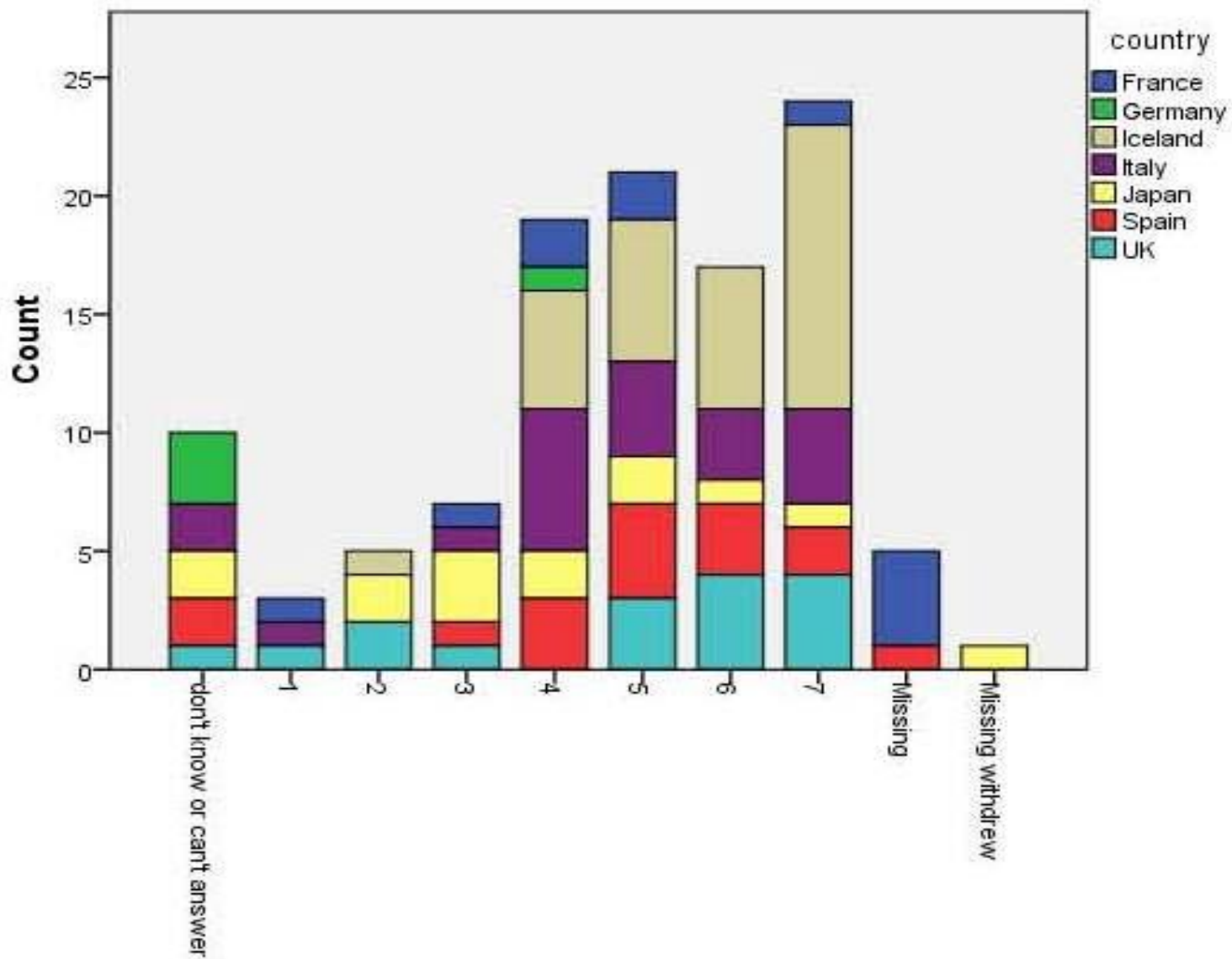
## Structure of EORTC QLQ-SWB36

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)



(38) Rating for spiritual wellbeing

## 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

## Assessment/measurement – intervention

**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



## Assessment/measurement – intervention

**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