



Spiritual Wellbeing Module

EORTC SWB-40

Teresa Young

Lynda Jackson Macmillan Centre

Mount Vernon Hospital

Northwood Middlesex

HA6 2RN

UK

Bella Vivat

Brunel Univ

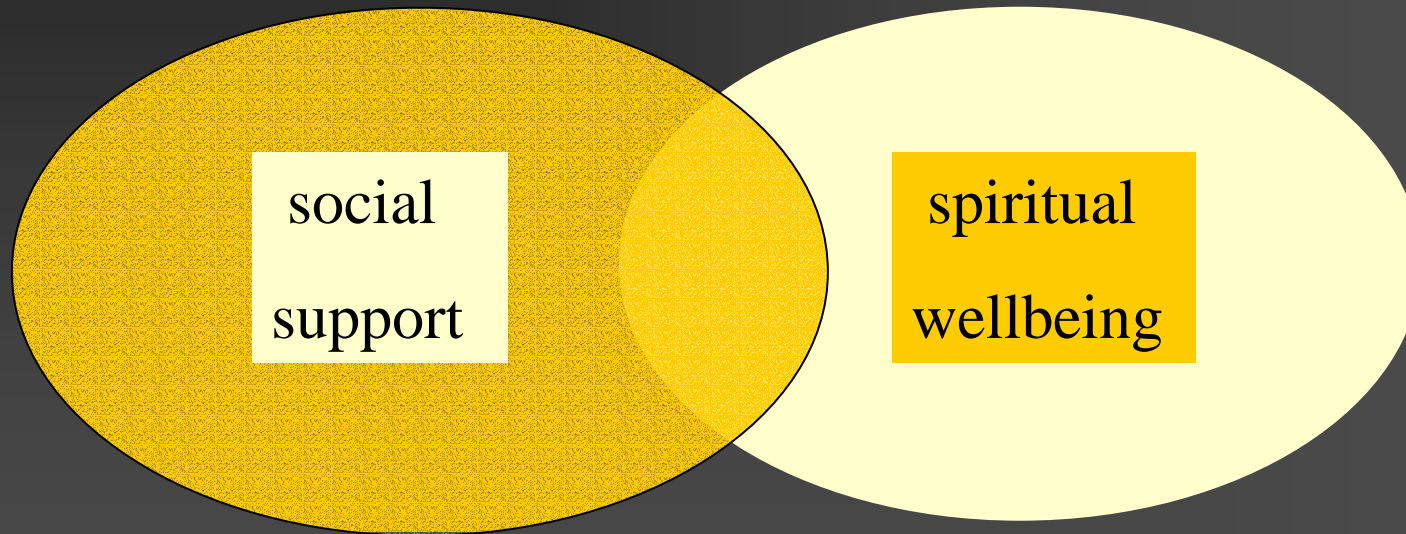
Collaborators

- Adriaan Visser - the Netherlands
 - Alexander de Graeff - the Netherlands
 - Bart van den Eynden – Belgium
 - Bernhard Holzner - Austria
 - Carlo Garufi – Italy
 - Fabio Efficace – Belgium/Italy
 - Karin Kuljanic Vlastic – Croatia
 - Valgerður Sigurðardóttir - Iceland
-

EORTC QLQ Module Development Guidelines

- Phase I – literature search/patient interviews to identify ‘issues’
 - Phase II – Generate ‘items’ from ‘issues’ for a provisional module
 - Report to MDC
 - **Phase III – Pilot test and finalise module**
 - Report to MDC
 - Phase IV – Field test EORTC module
-

Background/History



Spirituality - working definition

- The search for meaning in one's life, including the living of one's life on the basis of one's understanding of that meaning. May involve some or all of:
 - finding explanations for events and/or experiences
 - having or finding sustaining relationships with self and others
 - having or finding meaning beyond one's self and/or immediate events
-

Spiritual Wellbeing

- functional purpose of module
 - focus on issues with which help may be possible
 - monitor efficacy of spiritual interventions
 - “Spiritual impasse” - initiate discussions in areas which HCPs may find difficult to address
-

Numerical summary

- 1997-2001: 293 references
 - 17 existing “spiritual measures,” exploring wellbeing, spiritual orientation, or “spirituality” in general
-

Spirituality literature review data

	1996		1997-99		2000-1	
	number found	unique	number found	unique	number found	unique
PubMed	19	19	101	101	68	68
MedLine	18	0	84	1 (+ 13 SS)	45	10 (+ 5 SS)
CINAHL	0	0	5	1	6	4
ClinPsyc	7	4	26	5	11	3
Total unique		23		108		85

Issues list

- 84 issues
 - 29 relationships with self and others
 - 31 religious and/or spiritual beliefs and practices
 - 24 existential
-

Phase 1 (b) – interviews

- Whether patients have ‘ever’ had thoughts or feelings about a particular issue
 - Have you ever had thoughts and/or feelings about being in or out of control
 - Any similar issues?
 - Items to include / exclude
 - No QLQ-C30
-

Interviewees

- 7 Countries
 - Austria, Belgium, Croatia, Iceland, Italy, Netherlands, UK
 - 22 patients
 - 14 Female, 8 Male
 - 22 Health Care Professionals
 - 13 Female, 9 Male
-

Spiritual Wellbeing

- Provisional module with 69 items (from 84)
 - Two time frames
 - During the past week
I have felt that my life is worthwhile
 - General wellbeing in relation to spiritual/
existential concerns
I believe in life after death
-

Current Status

- Items very complex to translate
 - Too many for provisional module
 - Too expensive for commercial translation prior to pilot testing in Phase III
 - Deviate from guidelines and delete some issues on basis of pre-testing
-

Spiritual Wellbeing

- 17 (+1) interviews in UK, Italy & Iceland
 - Male and female, range of ages, diagnosis and religious/non religious beliefs
 - 10 – 30 minutes to complete
 - Debriefing interview
-

Inclusion Criteria

- There should be responses in 3 or 4 of the response categories (*not at all, a little, quite a bit, very much*).
 - Less than 50% of the responses should be in the response categories at the extremes (*i.e. Not at all or Very much*)
 - No more than 1 missing response per country and no more than 4/17 overall
-

Inclusion Criteria

- Prevalence (% scoring $\frac{1}{2}$ or $\frac{3}{4}$)
 - I have felt at peace with myself
 - I have worried about future of people important to me
 - I have reflected on my past
 - Correlations coefficients between items
 - Ranking data (from phase I)
 - Patient comments
 - Translatability
-

Final Decisions

- Emphasis on justifying deletion.
 - Less emphasis on justifying retention
 - Some items met exclusion criteria but were kept
 - Reduced from 69 to 40 items
 - Approved by MDC reviewers
-

EORTC SWB-40

- 3 domains
 - Relationships with self and with others
 - Existential issues
 - Religious/spiritual beliefs and practices
-

Phase III Protocol

- In draft since early March
 - Confirmed collaborators from Iceland, Norway, Austria, Germany and UK
 - Would like to recruit 150+ patients, so seeking more collaborators
 - Need to arrange professional translations through QLU
-

Eligibility

- Patients with advanced/incurable cancer, but not necessarily in the last few weeks of life.
 - (+ other diagnosis with terminal prognosis e.g. Multiple Sclerosis, Motor Neurone Disease, Heart Failure).
 - Aiming for at least 40% male
-

Method

- Self-completion of EORTC SWB-40
- Debriefing interview by experienced researcher
- Reports for translation pilot testing on first 2-3 patients, then 10 overall

BUT

- Administration of questionnaire may of itself be a spiritual intervention for some patients
-

Method

- Is it feasible for patients to self-complete the questionnaire?
 - How important is the debriefing interview?
 - Do the patients need an opportunity to discuss the issues raised?
 - ? Develop debriefing questionnaire for the researcher
-

Contact Details

- Teresa.young@mvh-ljmc.org
-