

Measures of spiritual issues for palliative care patients:

A literature review

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ABSTRACT

Members of the EORTC Quality of Life Group are developing a standalone functional measure of spiritual wellbeing for palliative care patients, which will have both a clinical and a measurement application. This paper discusses data from a literature review, conducted at two time points as part of the development process of this instrument. The review identified 29 existing measures of issues relating to patients' spirituality or spiritual wellbeing. 22 are standalone measures, of which 15 can be categorised as substantive (investigating the substance of respondents' beliefs), and 7 as functional (exploring the function those beliefs serve). However, perhaps owing to the lack of consensus concerning spirituality or spiritual wellbeing, the functional measures all have different (although sometimes overlapping) dimensions. In addition, they were all developed in a single cultural context (the US), often with predominantly Christian participants, and most were not developed with palliative care patients. None is therefore entirely suitable for use with palliative care patients in the UK or continental Europe.

Key words: spirituality, spiritual wellbeing, questionnaire, quality-of-life, cross-cultural

1. INTRODUCTION

The Quality of Life Group (QLG) of the European Organisation for Research and Treatment of Cancer (EORTC) aims to develop reliable and valid instruments for measuring the quality of life of cancer patients participating in international clinical trials.¹ It has been argued generally that studies which use quality of life as an endpoint should take people's religious, spiritual and/or existential concerns into account, since such concerns play a role in individuals' assessments of their quality of life.^{2:3} More specifically, although clinical trials do not currently specifically investigate interventions for patients' spiritual needs, research studies may evaluate such interventions alongside clinical trials, and suitable outcome measures may be helpful for such studies.^{4:5} Spiritual wellbeing may also have a role to play in people's decisions to participate in clinical trials,⁶ and tools to systematically investigate this could be useful.

People's spirituality and/or religion and/or personal beliefs may provide them with a sense of wellbeing in ways such as giving structure to their experience and helping them cope with difficulties and ascribe meaning to spiritual and personal questions.^{2: 1409} Spiritual, religious and/or existential issues may therefore increase in relevance when people are diagnosed with cancer, and when they receive cancer treatment,⁷ and may be particularly significant for people with advanced disease; it has been argued that people are partly enabled to endure suffering by maintaining hope, in one or both of two ways: i) trusting in a higher being and ii) finding meaning through relationships with a higher being and/or with other people.^{8: 828} Many people who are seriously ill say that existential issues have become more important to them since they became ill,³ and so: '[h]ealth care providers must recognize that, in informing patients that they have a life-threatening illness, they are impacting on the existential domain.'^{3: 582}

Palliative care explicitly acknowledges this in its aim of addressing patients' spiritual needs alongside their physical, social, and psychological needs.⁹ However, research has shown that health care professionals (HCPs) may inaccurately assess patients' spiritual needs,^{10;11} and, linked to this, often find it difficult to initiate discussion related to those needs.^{12;13} It is therefore increasingly argued that palliative care should more systematically develop spiritual care or interventions to address patients' spiritual needs, and ways of assessing the effects of such interventions,¹⁴ and that a measure to assess their effects is therefore needed.^{4;5} A recent review of measures of end-of-life care specifically identifies a lack of robust measures in the area of spirituality, and argues that developing such measures should be a research priority.¹⁵

However, there is currently little clarity or consensus concerning what patients' spiritual needs are and what spiritual care or spiritual interventions might be.^{8;16} Patients and HCPs place markedly different values on religious and spiritual beliefs,^{17;18} and vary widely in their perceptions of spirituality, and, therefore, in their experiences of spiritual wellbeing or, conversely, spiritual distress.¹⁹ This variation occurs both between individuals with no religious affiliation and also between people who have religious beliefs (so, for example, there are denominational differences between Christians²⁰).

The lack of any single agreed definition of spiritual need or spiritual care may be because spiritual pain or distress is specific to an individual. Each potentially causative factor, therefore, has to be understood in terms of its subjective significance and meaning for the individual.²¹ Thus, each person defines their own spiritual needs, so spiritual care may not mean providing answers to a person's spiritual questions, but rather listening to them and taking them seriously;¹⁶ that is, accompanying and supporting an individual in their exploration of their particular understanding of spirituality¹³ and in their development of their own sense of spiritual wellbeing.²²

Thus, assessment of a person's spiritual wellbeing, by directing that person's attention to issues related to spiritual wellbeing, may itself be an intervention, in the same way as it has been argued that a quality of life assessment can be an intervention, since such an assessment increases both patients' and HCPs' awareness of quality of life issues.²³ Similarly, Cohen et al. claim that their instrument, the McGill Quality of Life Questionnaire (MQOL) (which includes existential issues), has both a measurement function and a clinical application, since it is of use clinically 'in initiating the discussion of topics that are often otherwise difficult to discuss and therefore are often neglected.'^{3: 584} Developers of measures in this area therefore need to recognise the potential dual role of such measures as tools for both assessment and intervention.

In 2001, members of the EORTC QLG began developing a measure of spiritual wellbeing for patients receiving palliative care for cancer.^{24;25} By identifying and measuring the extent of patients' spiritual wellbeing, the final instrument will be a useful tool for measuring the efficacy of those interventions which claim to address patients' spiritual needs. As a standardised assessment of the spiritual aspect of palliative care, the measure will therefore be useful for systematic studies of hospice care and of palliative care in other settings.

The measure, like the MQOL, will also have a clinical application. It will provide patients with an opportunity to indicate areas where they have religious, spiritual and/or existential concerns. So (as noted above) it may form the first step in a spiritual intervention, while also assisting HCPs to begin identifying and assessing patients' concerns in this area, including whether patients might benefit from additional support from appropriate specialists in religious, spiritual, or pastoral care, such as further exploration of each patient's particular religious, spiritual and/or existential concerns, if relevant.

This paper discusses findings from a literature review conducted as part of the development process of this new measure, following EORTC QLG module development guidelines for developing modules or measures of quality-of-life for people with cancer.²⁶

2. METHOD

The initial intention was to develop a measure of spirituality for palliative care patients, building on earlier work conducted by members of the EORTC QLG.²⁷ As noted, there is little consensus on spiritual needs, and it is frequently commented ^{e.g. 28: 1534; 29: 549-50; 20: 631} that it is difficult, if not impossible, to reach complete agreement on a definition of spirituality. Nevertheless, a working definition of spirituality was necessary to guide the literature review, and, drawing on existing definitions,^{2; 30; 31} and discussion with potential collaborators, this was agreed as follows:

Spirituality is the search for meaning in one's life and (includes) the living of one's life on the basis of one's understanding of that meaning. It may involve some or all of the following: having or finding: (i) sustaining relationships with self and others; (ii) meaning beyond one's self; (iii) meaning beyond immediate events; (iv) explanations for events and/or experiences.

However, as the detailed review of the literature proceeded, it became apparent that it was necessary to clarify the focus of the measure. A key decision was whether it should be functional or substantive.

A functional approach to spiritual assessment explores constructs such as spiritual health or spiritual wellbeing. It 'is concerned with how a person finds meaning and purpose in life and with

the behavior, emotions, relationships and practices associated with that meaning and purpose ... [and inquires] ... in an open-ended way about a person's ultimate concern.^{32: 793} That is, a functional approach to spiritual assessment explores the function served by an individual's set of beliefs and activities, or how people's behaviours and activities relate to fundamental questions of existence.^{29: 550}

A substantive measure, on the other hand, explores areas such as respondents' spiritual beliefs, spiritual experiences, or their spiritual orientation, so focusing on the content, or the substance of people's religious/spiritual beliefs. Thus, this kind of measure enquires about the detail of a person's religious, spiritual and/or existential beliefs and understandings, and/or whether they match a predetermined set of beliefs and understandings, asking questions such as whether or not a person believes in God.^{32: 793}

A functional measure, therefore, unlike a substantive measure, does not investigate the detail of an individual's beliefs, although it may indicate that they may be important for an individual's spiritual wellbeing. A functional measure may include a few substantive questions concerning people's spiritual beliefs and experiences, such as "do you believe in God?" so that a person's responses to subsequent questions about God are meaningful. However, a functional measure does not include more detailed questions, such as what form or forms the person believes God has. Thus, a functional measure might identify whether or not people have religious or spiritual beliefs, which may shape their spiritual wellbeing, and so be relevant for determining the particular help which they may require subsequently, but it would not explore the content of those beliefs in any detail. Such an exploration, if this were relevant, might form part of a later intervention.

A discussion paper was circulated to potential collaborators in order to clarify whether to develop a functional or a substantive measure. It was agreed that the measure would be functional, exploring people's spiritual wellbeing, that is, their perceptions of the spiritual issues which arise for them, rather than a substantive measure of their spirituality, which would explore the detail of their spiritual, religious and/or existential beliefs. This decision was taken concurrently with clarifying the aims of the measure, as follows:

1. As noted above, exploring spiritual/existential issues is potentially an intervention, or can be the first step in an intervention. It was therefore decided that the measure should have an explicit clinical application, providing a means of initiating discussions to explore potentially sensitive and/or difficult areas. A functional measure would be the best tool for this, since it would enable the identification of areas of reduced wellbeing.

2. In line with the research framework of the EORTC QLQ,¹ the measure should also be capable of measuring and/or identifying the efficacy of interventions which seek to address spiritual needs. A functional measure would be more appropriate for this purpose, since, by focusing on how a patient's particular beliefs function in their daily life, it would be more sensitive to change than would a substantive measure of the detail of those beliefs.

Having agreed to produce a functional measure of spiritual wellbeing (SWB), a working definition of SWB was then developed. This had 3 dimensions:

- (a) relationships with self and others
- (b) existential issues
- (c) specifically religious and/or spiritual issues.

As noted above, spirituality had previously been defined as having or finding:

- (i) sustaining relationships with self and others
- (ii) meaning beyond one's self
- (iii) meaning beyond immediate events
- (iv) explanations for events and/or experiences.

Of these, dimension (i) parallels dimension (a) of SWB, while (ii), (iii) and (iv) may be either entirely contained within dimension (b) (for a person who has no spiritual or religious beliefs, such as a humanist) or within both (b) and (c) (for people who have specific religious or spiritual beliefs) (figure 1).

[figure 1 here]

This definition of SWB then framed the literature review, which was conducted at two time points, first when the study began in 2001, and second, to update the first, in 2007.

An earlier EORTC QLG project, developing a measure of spirituality for palliative care patients, ended in 1998.²⁷ The current study had access to this earlier work, including its literature review, which was conducted to Sept 1996. The first stage of the literature review, conducted when the study began, therefore covered the five-year period Sept 1996 - Sept 2001. The second stage, conducted in Sept 2007, covered a six-year period, Sept 2001 - Sept 2007.

Four databases – PubMed, MedLine, Cinahl and ClinPsyc – were searched on both occasions, using the search terms “cancer” AND “spiritu*” (“spiritu*” was used rather than “spirit*” so as to exclude references to alcohol and to terms such as “fighting spirit”).

In the time period Sept 1996 - Sept 2001 216 references were identified which, on the basis of their abstracts, appeared to be possibly relevant. Following a more detailed examination of this group of references, the full texts of 57 papers were obtained. Another 56 “key references” (defined as those references prior to 1997 which were cited in more than 1 of the references obtained for Sept 1996 - Sept 2001), were also obtained. All the references identified in the previous EORTC QLG study were considered as part of this process.

In the second time period, Sept 2001 - Sept 2007, over 850 possibly relevant references were found, over 500 of these in PubMed alone. This highlights and confirms that, as is frequently commented, ^{e.g. 33} interest, and related research, in spirituality has increased in recent years. The possible reasons for this are varied and complex, but chief among them are probably an increasing focus on spirituality in health policy ^{e.g. 34} and, linked to this, a growing awareness of the dearth of robust research studies in this area.¹⁵

The measures identified in the two phases of the literature review were examined systematically, with a particular focus on the existing standalone functional measures, and comparing their dimensions and items to the guiding definition of SWB.

3. RESULTS

3.1 Spiritual measures

The papers obtained included 29 relevant measures. 23 of these measures explore aspects of spirituality and/or spiritual health (for example, spiritual wellbeing, spiritual needs, spiritual

orientation, or spiritual beliefs). Six are measures of quality-of-life which include spiritual and/or existential issues as a dimension.

Eight of the 29 measures are functional: FACIT-Sp-Ex (Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being);^{35;36} JAREL (Spiritual Well-Being Scale);³⁷ MiLS (Meaning in Life Scale);³⁸ MPS (Mental Physical and Spiritual Wellbeing Scale);³⁹ SHI (Spiritual Health Inventory);¹⁰ SNI (Spiritual Needs Inventory);⁴⁰ SpIRIT (Spiritual Needs Related to Illness Tool);⁴¹ and SWBS (Spiritual Well-Being Scale)^{42;43} (table 1).

15 measures are substantive: the Beliefs and Values Scale;⁴⁴ ESI (Expressions of Spirituality Inventory);⁴⁵ II (Integration Inventory);⁴⁶ INSPIRIT (Index of Core Spiritual Experience);⁴⁷ Royal Free interview for religious and spiritual beliefs;⁴⁸ SAS (Spiritual Assessment Scale);⁴⁹ SBI (Spiritual Belief Inventory);⁵⁰ SEI (Spiritual Experiences Index);⁵¹ SIBS (Spiritual Involvement and Beliefs Scale);⁵² SOI (Spiritual Orientation Index);⁵³ SPIRITual history;⁵⁴ Kuhn’s “spiritual inventory;”⁵⁵ SpREUK;⁵⁶ SpS (Spiritual Perspective Scale);⁵⁷ and WHOQOL SRPB (Spiritual Religious and Personal Beliefs)⁵⁸ (table 2).

The remaining six measures are general measures of quality-of-life which include spiritual and/or existential issues: HQLI (Hospice Quality of Life Index);⁵⁹ LEQ (Life Evaluation Questionnaire);⁶⁰ Missoula-VITAS[®] quality of life index;⁶¹ MQOL (McGill Quality of Life Questionnaire);² NA-ACP (Needs Assessment for Advanced Cancer Patients);⁶² and WHOQOL¹ (table 3).

[tables 1, 2 & 3 here]

The functional measures investigate spiritual health (e.g. SHI¹⁰), spiritual well-being (e.g. FACIT-Sp-Ex,^{35;36} JAREL,³⁷ MPS,³⁹ SWBS^{42;43}), or spiritual needs (e.g. SNI⁴⁰, SpIRIT⁴¹). As discussed previously, such measures generally focus on activities, feelings and relationships. Typical items are: “I feel accepted and forgiven despite some past actions” (SHI¹⁰), “I accept my life situations” (JAREL³⁷), “I share insights into life with close people” (MPS³⁹).

Conversely, substantive measures investigate spirituality (e.g. SAS⁴⁹), spiritual orientation (e.g. SOI⁵³), spiritual and/or religious beliefs (e.g. Royal Free interview,⁴⁸ SBI,⁵⁰ SIBS⁵²) or spiritual experiences (e.g. INSPIRIT,⁴⁷ SEI⁵¹). Such measures predominantly explore beliefs, concepts or understandings, with typical items such as: “In the future, science will be able to explain everything” (SIBS⁵²) or “Life and death follows a plan from God” (SBI⁵⁰), and less frequently address activities or practices (for example: “I make a conscious effort to live in accordance with my spiritual values” (SEI⁵¹)).

20 of the 29 measures identified were examined in detail: all eight functional measures, five measures of quality-of-life, and (so as to be sure that all relevant substantive issues were identified) seven of the substantive measures: INSPIRIT, Royal Free interview, SBI, SEI, SIBS, Maugan’s SPIRITual history and Kuhn’s “spiritual inventory.” One general measure (NA-ACP) and the other eight substantive measures (the Beliefs and Values Scale, ESI, II, SAS, SOI, SpREUK, SpS, and WHOQOL SRPB) were not examined in detail, since they are less frequently used than the measures assessed, and it was considered that seven substantive measures were sufficient to achieve saturation of relevant substantive issues.

3.2 Detailed examination of the functional measures

Seven of the eight functional measures are standalone measures, and so potentially similar to the measure under development. (The eighth functional measure (MPS³⁹) is not standalone, but one of its three dimensions, with ten items, is Spiritual Wellbeing). The characteristics of the participants in the development of these seven measures were examined, and the content of each measure analysed in relation to the framing definition of SWB.

3.2.1 Participant characteristics

The characteristics of the participants in the development of all of these measures is problematic for two reasons. First, all of the measures were initially developed in the US (although a cross-cultural validation of FACIT Sp-Ex³⁵ was later conducted with participants in the US and in Puerto Rico). However, measures, particularly of complex areas such as spirituality or spiritual wellbeing, should be developed cross-culturally as far as possible, in order to eliminate concepts which are not shared across cultures.⁶³ Subtle conceptual differences between cultures may impede understanding and make later translation difficult or even impossible. Such differences should therefore be explored and resolved when the measure is first being developed, a process termed “linguistic validation” by the MAPI Research Institute.⁶³

Second, only one of the measures – SNI⁴⁰ – was entirely developed with palliative care patients (a total of 100 patients in four outpatient hospices and one inpatient hospice). 3 measures: FACIT-Sp-Ex,³⁴ MiLS,³⁸ and SpIRIT⁴¹ were developed with cancer patients, but not specifically palliative care patients. The fifth measure, SHI,¹⁰ was developed with nurses and patients in oncology settings, but no further details are given concerning the characteristics of the patients who participated. The sixth measure, JAREL,³⁷ was developed with people aged 65-85, whose health statuses ranged from good physical health to terminal illness, but the number of

participants in each category is unknown. The seventh measure, SWBS,⁴² was developed with student participants with no stated illnesses.

3.2.2 Content of the seven standalone functional measures

All the items from all seven of the standalone functional measures fit within one of the three dimensions of the framing definition of SWB, as shown in table 4. (Please note that one dimension of SWB is “relationships with self and others,” but in table 4, for purposes of comparison, this dimension is subdivided into “relationships with self” and “relationships with others”).

[table 4 here]

Table 4 shows that only two of the seven standalone functional measures contain items which cover all three dimensions of SWB. All the measures include items in one or two dimensions which are broadly equivalent to the existential dimension of SWB. Six of them include items which fit the religious dimension of SWB (SHI¹⁰ is the only measure which does not). Six include items relating to the respondent’s relationship with him- or herself. However, only three measures address relationships with others, and, as noted, one of these (SHI¹⁰) does not include any religious items.

Thus, only two of the seven standalone functional measures identified in the literature review are possible equivalents to the measure being developed by the EORTC QLG. As noted, the Spiritual Needs Inventory (SNI)⁴⁰ is the only one of these seven measures which was developed with palliative care patients. The items in its five dimensions (outlook, inspiration, spiritual activities, religion and community) all relate to the three dimensions of SWB, and it has a total of

17 items, so is of manageable length for palliative care patients. However, SNI was developed in an exclusively US context, with participants who were overwhelmingly Caucasian (89%) and Protestant (71%), and, for such a short measure, some of the items are rather limited or are repetitive or redundant. For example, the “spiritual activities” dimension contains three items: “read inspirational material,” “use inspirational material,” “use phrases from a religious text.” These items overlap to some extent, and the term “use” is vague and could be confusing; it might also be difficult to translate this concept into other languages. The “community” dimension of SNI also has three items: “be with family,” “be with friends,” “have information about family and friends.” These items are also rather vague, and limited, since they do not explore the detail of the interaction between the respondent and their family or friends.

The other measure with some similarities to the one being developed by the EORTC QLG is the Spiritual Needs Related to Illness Tool (SpIRIT).⁴¹ This is a lengthy, detailed questionnaire, with 8 dimensions and 50 items, many of which fit within the dimensions of SWB. However, the meaning of some of the items in SpIRIT is unclear or vague, for example: “get right with God,” “have faith within myself,” “be with others I consider to be family.” This latter issue, as with SNI’s “be with family,” “be with friends,” lacks specific detail regarding the nature of the relationship with family/friends, such as whether the respondent feels love or forgiveness towards and from others. Indeed, although two of its dimensions are ‘giving love to others’ and ‘receiving love from others,’ SpIRIT does not mention love in any of its relationship items (the closest phrases to this are “return others’ kindnesses,” “be appreciated by others,” and “be with others I consider to be family”), and most of its items focus on the respondent’s feelings rather than the detail of their interactions with others. Nor does SpIRIT include items relating to difficulties with maintaining beliefs, or changes in beliefs, which may be particularly important for people with life-limiting illnesses.³³

An additional limitation of SpIRIT is that, as with all the measures, it was developed solely in the US. It was also developed in a single setting: a university medical centre in the southwest US. Development participants were 156 people with cancer and 68 caregivers. 87% of participants were practising Christians, and most of the people with cancer who participated had conditions which were not considered to be life threatening (they were predominantly (67%) white men recently diagnosed with prostate cancer). Both the length and the content of the measure reflect this. At 50 items, SpIRIT is too long to use with palliative care patients, who may become fatigued easily, and some items which might be relevant when people are first diagnosed with cancer might be inappropriate for people reaching the ends of their lives, for example: “return others’ kindnesses”; “protect my family from seeing me suffer”; “realize that there are other people who are worse off than me”; “become aware of positive things that have come with my illness”; “believe that God has healed or will heal me.”

4. CONCLUSIONS

This paper has considered findings from a literature review of measures of spiritual issues for palliative care patients, conducted at two time points – September 2001 and September 2007 – and framed by a definition of spiritual wellbeing (SWB) as having three dimensions: (a) relationships with self and others, (b) existential issues, and (c) specifically religious and/or spiritual issues. The literature review identified 29 existing measures which address spiritual issues. Seven of these are standalone functional measures, and could potentially, therefore, serve a similar purpose to the measure being developed by the EORTC Quality of Life Group.

However, only two of these measures (SNI⁴⁰ and SpIRIT⁴¹) contain items which relate to the entirety of all three dimensions of the framing definition of SWB, and each of these measures has significant limitations.

Key limitations of both measures are that they were developed solely in the US, and with predominantly Christian participants, yet the cultural specificity of measures in complex areas such as spiritual wellbeing means that it is especially important that such measures should be developed cross-culturally as far as possible. Each measure also has its own particular limitations.

Of all the functional measures reviewed, SpIRIT is the closest to the measure currently under development, with many items which fit within the three dimensions of SWB. However, perhaps because it was not specifically developed with palliative care patients, SpIRIT is too long (50 items) for this population, omits some issues which this population might find important, and includes other items which would be inappropriate for people at the end of their lives.

In contrast, SNI was developed with hospice patients, so is more likely to be relevant for palliative care patients, and, as a brief measure (17 items), it would be manageable by this population. However, for such a brief measure some of its items overlap or are repetitive, and the meaning of some other items is vague.

Thus, this literature review has not identified any currently published functional measure of issues relating to spiritual wellbeing which is equivalent to the one being developed by the EORTC QLQ. The literature review also corroborates the claim of Mularski et al.¹⁵ that there is a dearth of robust measures relating to spirituality in end-of-life care. The EORTC QLQ project therefore continues to be relevant, and of particular value for palliative care patients across Europe.

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