Assessment of spiritual suffering in the cancer context: A systematic literature review

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ABSTRACT

Objective: An important goal of cancer medicine is relief of patients’ suffering. In view of the clinical challenges of identifying suffering patients, we sought to identify valid instruments for assessing the spiritual suffering of people diagnosed with cancer.

Method: A systematic review of the literature was conducted in the Medline, Embase, the Cochrane Library, and PsycINFO databases seeking assessment instruments that measure either suffering or one of its synonyms or symptoms. The psychometric properties of the identified measures were compared.

Results: A total of 90 articles were identified that supplied information about 58 measures. The constructs examined were: suffering, hopelessness/demoralization, hope, meaning, spiritual well-being, quality of life where a spiritual/existential dimension was included, distress in the palliative care setting and pain, distress or struggle of a spiritual nature. The Pictorial Representation of Illness and Self Measure (PRISM) (patient completed) was the most promising measure identified for measuring the burden of suffering caused by illness due to its ease of use and the inclusion of a subjective component.

Significance of Results: Although the appropriateness of any measure for the assessment of spiritual suffering in cancer patients will depend on the context in which it is intended to be utilized, the PRISM is promising for measuring the burden of suffering due to illness.

KEYWORDS: Cancer, Assessment, Suffering, Spirituality, Systematic review

INTRODUCTION

Optimal care of people with cancer incorporates the effective management of physical, psychological, social, and existential/spiritual well-being, and strives to alleviate suffering. Our recent systematic review investigating the experience and management of suffering in cancer (Best et al., 2014) concluded that spiritual suffering is defined as “an all-encompassing, dynamic, individual phenomenon characterized by the experience of alienation, helplessness, hopelessness, and meaninglessness in the sufferer that is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality.” Surrogate terms, antecedents, and consequences of suffering were described and recommendations were made to address spiritual suffering in cancer patients. However, a reliable means for assessing suffering is needed in order to achieve this goal.

Potential barriers to recognition of suffering in cancer patients include the difficulty patients have in articulating their suffering, either due to an inability to find the appropriate vocabulary or an
unwillingness to burden others (Boston et al., 2011; Cherny et al., 1994; Younger, 1995). Assistance may be needed to voice the conflict, which is known to be beneficial for the sufferer (Blinderman & Cherny, 2005). However, healthcare workers may not be able to identify patient distress or may be unwilling to acknowledge it due to the biopsychosocial paradigm of Western medicine that ignores the spiritual (Arman et al., 2004; Ferrell, 1993). Healthcare staff may fail to respond to suffering even if they recognize it (Rodgers & Cowles, 1997), perhaps because of their own death anxiety (Kahn & Steeves, 1995). Patients may wait for a cue that never comes or just assume that the staff are too busy to listen (Strang, 1997). Some sufferers feel a lack of a “safe space” in which to discuss their fears (Moore et al., 2004). This situation highlights the need for reliable tools for assessment of suffering that are not dependent on patients finding the opportunity to voice their distress.

Information about the assessment of suffering in the context of cancer is not easily accessible, nor have the relative benefits and disadvantages of the available assessment tools been compared. (Rodin, 2003). Previous reviews of the assessment of suffering have been limited to the psychological aspects of distress (Carlson & Bultz, 2003; Carlson et al., 2012; Kelly et al., 2006) or focused on the end-of-life setting (Krikorian et al., 2013). To address this gap in the literature, we undertook a systematic review of measures of spiritual suffering in people diagnosed with cancer, including currently treated, palliative, and survival populations.

METHOD

Search

Between April and June of 2012, a systematic search of the literature was conducted to identify all English-language studies published between 1992 and 2012 that focused on assessment of suffering in cancer patients. The following databases were systematically searched: MEDLINE, EMBASE, the Cochrane Library, and PSYCINFO. To ensure a sufficiently broad range of conceptualizations of suffering, the search strategy was drafted using an iterative process. Results from preliminary searches were employed to develop a list of concepts identified in the literature as synonymous with suffering, or potentially measurable “symptoms” of suffering and their antonyms (see Tables 1 and 2). The identified search terms (see Table 3) were entered in each of the databases listed above.

In order to be included, reports had to: (1) be published in a peer-reviewed journal; (2) focus on adults (aged 18 years and above) who had been diagnosed with cancer; (3) report on outcomes relevant to the review question (i.e., assessment of suffering in cancer patients); and (4) assess tools/instruments that measured either suffering or one of its synonyms or symptoms (as listed in Tables 1 and 2).

Reports were excluded if they: (1) focused on children with cancer, parents of children with cancer, other carers of patients with cancer, or adult survivors of childhood cancers; (2) focused on suffering in patient groups with and without cancer, unless the results were reported separately for cancer patients, or unless the sample was predominantly cancer patients (e.g. 95% or more); (3) were books, book chapters, dissertation abstracts, or conference abstracts; (4) utilized or reviewed measures of interest without reporting the psychometric properties of the instrument; or (5) focused predominantly on spiritual or existential “issues” or “concerns.”

### Table 1. Terms used synonymously with “suffering”

<table>
<thead>
<tr>
<th>Concept</th>
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<tbody>
<tr>
<td>Suffering</td>
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<tr>
<td>Existential distress</td>
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<td>Existential suffering</td>
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<td>Existential pain</td>
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<tr>
<td>Spiritual distress</td>
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<td>Spiritual suffering</td>
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<td>Spiritual pain</td>
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<tr>
<td>Psychospiritual distress</td>
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<tr>
<td>Psychoexistential suffering</td>
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<tr>
<td>Total pain</td>
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<tr>
<td>Demoralization</td>
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</tbody>
</table>

### Table 2. Potentially measurable “symptoms” of suffering (and their “opposites”)

<table>
<thead>
<tr>
<th>Concept</th>
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</thead>
<tbody>
<tr>
<td>Hopelessness, despair</td>
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<tr>
<td>Loss of meaning</td>
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<tr>
<td>Sense of meaning/finding meaning</td>
</tr>
<tr>
<td>Sense of coherence</td>
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<tr>
<td>Purpose in life</td>
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<tr>
<td>Hope</td>
</tr>
<tr>
<td>Dignity</td>
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<tr>
<td>Transcendence</td>
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<td>Spiritual well-being</td>
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<td>Peace</td>
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<tr>
<td>Faith</td>
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<tr>
<td>Crisis of faith</td>
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<tr>
<td>Desire for (hastened) death</td>
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</tbody>
</table>

Downloaded from https://www.cambridge.org/core. IP address: 54.70.40.11, on 29 Jan 2019 at 10:00:13, subject to the Cambridge Core terms of use, available at https://www.cambridge.org/core/terms. https://doi.org/10.1017/S1478951514001217
they were in fact reporting on “distress,” “pain,” “crisis,” “anguish,” or another synonym of “suffering.” There are a number of existing review papers that explore the former group of papers (Bresnahan & Merrill, 2000; Henoch & Danielson, 2009; Sulmasy, 2006). For these reasons, only the second group of papers were included in the present review.

All retrieved articles were reviewed against the selection criteria, and manual searches were conducted to identify any additional relevant articles not retrieved by the systematic search. Articles that employed or reviewed measures of interest without reporting the psychometric properties of the instrument (and therefore excluded from the search) were separately reviewed to generate a list of additional measures for which instrument development/validation studies were subsequently sought. We attempted as far as possible to include initial and key publications pertaining to the psychometric properties of an instrument, particularly if it was reported in the cancer context. Papers summarizing psychometric properties across multiple studies were deemed eligible for inclusion if no specific studies in the cancer context were available.

A flowchart presenting the results of the literature search is presented as Figure 1.

### Data Extraction

For each instrument/validation study the following data were extracted by LA and MB:

1. Properties of the measure: mode of administration; number of items; response scale; scoring.
2. Details of the initial and key validation samples.
3. Details of the item development process.
4. Information on any domains/subscales.
5. Information on reliability, validity, and responsiveness to change.

### RESULTS

Systematic searches of the literature resulted in identification of 90 articles presenting information about 58 measures, which appeared to assess either suffering or one of its synonyms or symptoms. The constructs examined by the eligible measures were: suffering, hopelessness/demoralization, hope, meaning, spiritual well-being, quality of life where a spiritual/existential dimension was included, distress in the palliative care setting and pain, distress or struggle of a spiritual nature. The psychometric properties of the selected measures are set forth in Table 4.

### Suffering

Two measures of suffering for which psychometric properties are available were identified: the Mini-Suffering State Examination (MSSE) (physician completed) (Aminoff et al., 2004) and the Pictorial Representation of Illness and Self Measure (PRISM) (patient completed) (Büchi et al., 2002).

#### Mini-Suffering State Examination (MSSE)

The MSSE is a brief clinician-administered measure of suffering that may be particularly useful with end-stage cancer patients who experience difficulties communicating their needs and/or expressing their...
suffering (Adunsky et al., 2008). It was originally developed in the context of dementia (Aminoff et al., 2004), but preliminary work has been done to explore its psychometric properties in the context of cancer (Adunsky et al., 2008).

Content validity is dependent on the clinical judgment of the scale’s designers, and there is no indication of further work seeking confirmation of appropriateness and comprehensiveness of items. The 10 items included on this scale do not necessarily encompass the full range of, nor even the most pressing dimensions of, suffering in cancer patients at the end of life, suggesting that this tool may be a useful starting point for measuring some types of suffering, but that further work exploring its content validity may be required.

Reliability overall appears adequate, though some of the items are fairly subjective (e.g., “suffering according to medical opinion” and “not calm”), and this was reflected by lower levels of observer agreement ($\kappa = 0.62$ and 0.64) on ratings for these two items (Aminoff et al., 2004).
<table>
<thead>
<tr>
<th>Construct</th>
<th>Measured</th>
<th>Tool</th>
<th>Description</th>
<th>Cancer Validation*</th>
<th>Domains</th>
<th>Reliability</th>
<th>Construct Validity (+/−)**</th>
<th>Responsiveness to Change (+/−)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering</td>
<td></td>
<td>MSSE (Aminoff et al., 2004)</td>
<td>Administration: clinician-rated Items: 10 Response scale: yes/no (1/0) Scores: range 0–10 0–3 reflects low level of suffering, 4–6 intermediate, 7–10 high</td>
<td>152 advanced cancer patients with &lt;1 month life expectancy Israel (Adunsky et al., 2008)</td>
<td>None specified</td>
<td>Physician 1, internal consistency: $\alpha = 0.735$ (Aminoff et al., 2004) Physician 2, internal consistency: $\alpha = 0.718$ (Aminoff et al., 2004) Interobserver reliability: $\kappa = 0.791$ (Aminoff et al., 2004) Internal consistency: $\alpha = 0.738$ (Adunsky et al., 2008)</td>
<td>+ (Aminoff et al., 2004)</td>
<td>+ (Adunsky et al., 2008)</td>
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<td></td>
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<td>PRISM (Buchi et al., 2002)</td>
<td>Administration: clinician administered and/or self-report (by post with stickers) Items: 1 Response scale: placement of &quot;illness&quot; disc on board. Perceived burden of suffering due to illness is distance in cm from centre of &quot;illness&quot; disc to center of &quot;self&quot; disc Size of &quot;illness&quot; disc (PRISM–R2) represents perceived severity of illness, range 1–3 (for three sizes of disc)</td>
<td>1299 long-term survivors of prostate cancer, endometrial cancer, non-Hodgkin’s and Hodgkin’s lymphoma The Netherlands (Wouters et al., 2011)</td>
<td>None specified</td>
<td>Test–retest reliability (2 hours) $r = 0.95$ (Buchi et al., 2002) Interrater reliability (6 hours) $r = 0.79$ (Buchi et al., 2002)</td>
<td>+ (Buchi et al., 2002; Buchi &amp; Sensky, 1999; Wouters et al., 2011; Wouters et al., 2008a)</td>
<td>+ (Buchi et al., 2002; Wouters et al., 2008a)</td>
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<tr>
<td>Hopelessness/ demoralization</td>
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<td>BHS (Beck et al., 1974)</td>
<td>Administration: self-report Items: 20 Response scale: true/false (0/1) Scores: range 0–20. Score of 8 or more reflects moderate to severe levels of hopelessness (Beck et al., 1993)</td>
<td>200 hospice inpatients with a diagnosis of cancer and a life expectancy of less than 6 months. United States (Abbey et al., 2006) 406 ambulatory patients with advanced lung or gastrointestinal cancer Canada (Nissim et al., 2010)</td>
<td>Three factors identified in initial study: feelings about the future (5 items); loss of motivation (8 items); future expectations (5 items) 161 Two factors identified in one cancer validation study: negative expectations (10 items; $\alpha = 0.86$); loss of motivation (10 items; $\alpha = 0.83$)</td>
<td>Internal consistency: $\alpha = 0.93$ (Beck et al., 1974) Internal consistency 20-item: $\alpha = 0.87$ 3-item: $\alpha = 0.69$ (Abbey et al., 2006) 7-item: $\alpha = 0.85$ (Abbey et al., 2006) 13-item: $\alpha = 0.89$ (Abbey et al., 2006)</td>
<td>+ (Abbey et al., 2006; Beck et al., 1974; Nissim et al., 2010)</td>
<td>+ (Abbey et al., 2006; Beck et al., 1974; Nissim et al., 2010)</td>
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<tr>
<td>Construct Measured</td>
<td>Tool</td>
<td>Description</td>
<td>Cancer Validation*</td>
<td>Domains</td>
<td>Reliability</td>
<td>Construct Validity (+/−/−)**</td>
<td>Responsiveness to Change (+/−/−)**</td>
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<td><strong>C</strong></td>
<td>CCM</td>
<td>Administration: self-report (paper or tablet)</td>
<td>Three adult cancer outpatient samples (n = 449) United States (Fortner et al., 2003)</td>
<td>None specified</td>
<td>Internal consistency (for all 3 samples combined) $\alpha = 0.89$ Alternate forms pen and paper and tablet: $r = 0.87$</td>
<td>+</td>
<td>? (Fortner et al., 2003) + (Abernethy et al., 2010)</td>
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<td>Items: 7 Response scale: 10-point Likert-type scales (0 = not a problem; 10 = as bad as possible) Scores: raw scores are converted to normalized t scores with mean of 50 and SD of 10</td>
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<tr>
<td><strong>C</strong></td>
<td>Demoralization scale (Jacobsen et al., 2006)</td>
<td>Administration: self-report Items: 7 Response options and scoring not specified</td>
<td>242 advanced cancer patients United States (Jacobsen et al., 2006)</td>
<td>None specified</td>
<td>Internal consistency: $\alpha = 0.78$</td>
<td>+</td>
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<tr>
<td><strong>C</strong></td>
<td>Demoralization scale (Kissane et al., 2004)</td>
<td>Administration: self-report Items: 24 Response scale: 5-point (0 = never, 1 = seldom, 2 = sometimes, 3 = often, 4 = all the time) Scores: range 0–96</td>
<td>100 patients with advanced cancer: Australia (Kissane et al., 2004) 100 inpatients with advanced cancer: Ireland (Mullane et al., 2009)</td>
<td>Loss of meaning (5 items) $\alpha = 0.87$ Dysphoria (5 items) $\alpha = 0.85$ Disheartenment (6 items) $\alpha = 0.89$ Helplessness (4 items) $\alpha = 0.84$ Sense of failure (4 items) $\alpha = 0.71$</td>
<td>Internal consistency: $\alpha = 0.94$</td>
<td>+ (Kissane et al., 2004) ? (Mullane et al., 2009)</td>
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<td><strong>C</strong></td>
<td>HAI</td>
<td>Administration: self-report Items: 8 Response scale: anchored statements each with three response options (0–2) Scores: range 0–16</td>
<td>Two advanced cancer samples (n = 583)</td>
<td>Factor analysis supported a one-factor model</td>
<td>Internal consistency: $\alpha = 0.87$ Average interitem correlation $r = 0.48$</td>
<td>+</td>
<td>?</td>
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</tr>
</tbody>
</table>
### 1. SISC (Wilson et al., 2004)

**Administration:**
- Clinician-administered
- Items: 1
- Response scale: 7-point scale (0 = none, 1 = minimal, 2 = mild, 3 = moderate, 4 = strong, 5 = severe, 6 = extreme)

69 palliative care (advanced) cancer patients
- Canada

**Single item Interrater reliability**
- +

**Test–retest (1–3 days)**
- $r = 0.98$

**Notes:**
- 1 or 2 indicates the experience of the symptom or concern is relatively low.
- 3 corresponds to an issue that is generally a significant problem. Higher scores are associated with a clear presence of a symptom or concern at a clinically important level with varying degrees of severity.

### 2. SIS (Cockram et al., 2009)

**Administration:**
- Self-report
- Items: 12
- Response scale: 4-point (0 = none of the time, 3 = most or all of the time)

112 outpatients with a diagnosis of colorectal or gastrointestinal cancer
- United States

**Basic SI score (no. of items scored >0):** range 0–12

**Severity score (sum of scores):** range 0–48

**Not specified**

**Internal consistency:**
- +

**Test–retest reliability:**
- (separate sample of psychiatric outpatients, timeframe not specified)

### 3. ADHS (Snyder et al., 1991)

**Administration:**
- Self-report
- Items:
  - 8 hope items + 4 filler items
- Response scale:
  - 4-point scale (1 = definitely false, 2 = mostly false, 3 = mostly true, 4 = definitely true)
- Scores: range 12–48

**Agency:**
- +
- (Fallah et al., 2011)

**Pathways:**
- $a = 0.63–0.80$

**Internal consistency:**
- +

**Test–retest reliability**
- (3-week) $r = 0.85$
- (8-week) $r = 0.73$
- (10-week) $r = 0.76$
- $r = 0.82$
<table>
<thead>
<tr>
<th>Construct Measured</th>
<th>Tool</th>
<th>Description</th>
<th>Cancer Validation*</th>
<th>Domains</th>
<th>Reliability</th>
<th>Construct Validity (+/−)**</th>
<th>Responsiveness to Change (+/−)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>HHS (Herth, 1991)</td>
<td>Administration: self-report</td>
<td>Items: 30</td>
<td>180 cancer patients (NB: this group was used for pretesting and pilot testing—not the final validation) United States</td>
<td>Temporality and future (cognitive–temporal) ( \alpha = 0.91 )</td>
<td>Internal consistency (population): Well adults ( \alpha = 0.92 ) Well elderly ( \alpha = 0.94 ) Elderly widow(er)s ( \alpha = 0.95 ) Test–retest reliability (3-week): Well adults ( r = 0.90 ) Well elderly ( r = 0.89 ) Elderly widow(er)s ( r = 0.91 )</td>
<td>+</td>
<td>?</td>
</tr>
<tr>
<td>HHI (Herth, 1992)</td>
<td>Administration: self-report</td>
<td>Items: 12</td>
<td>Two groups of adolescents and young adults with cancer (127 at various stages of treatment and 74 newly diagnosed) United States, Canada (Phillips-Salimi et al., 2007)</td>
<td>Temporality and future (cognitive–temporal) Positive readiness and expectancy (affective–behavioral) ( \alpha = 0.90 ) Interconnectedness (affiliative–contextual) ( \alpha = 0.87 )</td>
<td>Internal consistency: Acute ( \alpha = 0.98 ) Chronic ( \alpha = 0.96 ) Terminal ( \alpha = 0.94 ) Entire sample ( \alpha = 0.97 ) Domains: ( \alpha = 0.78–0.86 ) (Herth, 1992) Test–retest reliability (2-week) ( r = 0.91 ) (Herth, 1992) Internal consistency: Various stages ( \alpha = 0.84 ) Newly diagnosed ( \alpha = 0.78 ) (Herth 1992; Phillips-Salimi et al., 2007)</td>
<td>+ (Herth et al., 2007)</td>
<td>(Herth, 2000)</td>
</tr>
<tr>
<td>Measure</td>
<td>Administration</td>
<td>Items</td>
<td>Description</td>
<td>Response scale</td>
<td>Scores</td>
<td>Higher scores indicate</td>
<td>Internal consistency</td>
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<tr>
<td><strong>HDS</strong> (Nekolaichuk &amp; Bruera, 2004)</td>
<td>Administration: self-report</td>
<td>Items: 9</td>
<td>96 advanced (palliative) cancer patients, Canada (negative response and 7 the positive)</td>
<td>1 to 7</td>
<td>range 7–63</td>
<td>indicate an enhanced hope experience</td>
<td>+</td>
</tr>
<tr>
<td><strong>MHS</strong> (Miller &amp; Powers, 1988)</td>
<td>Administration: self-report</td>
<td>Items: 40</td>
<td>Satisfaction with self, others and life, Avoidance of hope threats, Anticipation of a future</td>
<td>5-point Likert-type format from 5 (strongly agree) to 1 (strongly disagree)</td>
<td>range 40–200</td>
<td>higher score indicates high hope</td>
<td>+</td>
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<tr>
<td><strong>NHS</strong> (Nowotny, 1989)</td>
<td>Administration: self-report</td>
<td>Items: 29</td>
<td>306 adults, (150 with and 156 without cancer), who had experienced a stressful event, United States</td>
<td>4-point Likert-type (strongly agree, agree, disagree, and strongly agree)</td>
<td>range 29–119</td>
<td>indicates high hope</td>
<td>+</td>
</tr>
<tr>
<td><strong>Meaning</strong></td>
<td>Administration: self-report</td>
<td>Items: 11</td>
<td>190 women with breast cancer (newly diagnosed and survivors), 200 women with breast cancer (within 2 years of diagnosis without metastasis), Hong Kong</td>
<td>Response options and scoring not specified</td>
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<td>+</td>
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<thead>
<tr>
<th>Construct Measured Tool</th>
<th>Description</th>
<th>Cancer Validation*</th>
<th>Domains</th>
<th>Reliability</th>
<th>Construct Validity (+/−)</th>
<th>Responsiveness to Change (+/−)</th>
</tr>
</thead>
</table>
| Constructed meaning scale (Fife, 1995) | Administration: self-report
Items: 8
Response scale: 4-point (1–4: strongly disagree; disagree; agree; strongly agree)
Scores: range 8–32 | 422 persons with a variety of types of cancer, at specified points in the illness trajectory. United States | None specified | Internal consistency $\alpha = 0.81$ | $+$ | $?$ |
| FACIT–Sp meaning subscale (Canada et al., 2008) | Administration: self-report
Items: 12
Response scale: 5-point (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much)
Scores: range 0–48 | 1,617 respondents, predominantly with cancer diagnoses (a)
131 cancer patients with mixed early stage and metastatic diagnoses (b)
240 long-term female cancer survivors (c)
8805 cancer survivors (d). United States, Puerto Rico | Meaning/faith subscale (8 items)
Meaning subscale (4 items)
Peace subscale (4 items)
Faith (4 items) | Internal consistency: $\alpha = 0.87$ $\alpha = 0.86$ $\alpha = 0.83$ $\alpha = 0.84$ $\alpha = 0.87$ |
| ICQ (Evers et al., 2001) | Administration: self-report
Items: 18
Response scale: 4-point (0 = not at all to 4 = completely)
Scores: range for each 6-item scale 0–24 | Helplessness (6 items)
Acceptance (6 items)
Perceived benefits (6 items) | Test–retest reliability (1 year, n = 81 RA, n = 67 MS) $r = 0.68$ to 0.79 |
| ICS (Kroz et al., 2009) | Administration: self-report
Items: 10
Response scale: 5-point (1–5)
Scores: range 10–50 | 57 cancer patients; 57 matching controls
(a) 17 patients with breast cancer
and 25 with colorectal cancer receiving chemo
(b) Germany | Inner resilience & coherence (8 items)
Range 8–40
Thermo-coherence (2 items) | Internal consistency: $\alpha = 0.91$ $\alpha = 0.85$ $\alpha = 0.85$ |

* Evidence of responsiveness to change from a number of intervention studies (e.g., Ando et al., 2010; Breitbart et al., 2012; Henry et al., 2010)
<table>
<thead>
<tr>
<th>Instrument/Version</th>
<th>Administration</th>
<th>Items</th>
<th>Response Scale</th>
<th>Scores</th>
<th>Subscales</th>
<th>Alpha</th>
<th>Range</th>
<th>Internal Consistency</th>
<th>Test–Retest Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>LAP (Reker &amp; Peacock, 1981)</td>
<td>self-report</td>
<td>56</td>
<td>7 point (1 = strongly disagree to 7 = strongly agree)</td>
<td>Range unclear</td>
<td>Life purpose (9 items) $\alpha = 0.83$ Existential vacuum (7 items) $\alpha = 0.75$ Life control (6 items) $\alpha = 0.78$ Death acceptance (6 items) $\alpha = 0.70$ Will to meaning (6 items) $\alpha = 0.57$ Goal seeking (5 items) $\alpha = 0.66$ Future meaning to fulfill (5 items) $\alpha = 0.55$</td>
<td>+</td>
<td>?</td>
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<tr>
<td>LAP–R (Reker, 1992)</td>
<td>self-report</td>
<td>48</td>
<td>7 point (1 = strongly disagree to 7 = strongly agree)</td>
<td>Range 16–112</td>
<td>Life purpose Coherence Choice/responsibleness Death acceptance Existential vacuum Goal seeking Composite scores: Personal Meaning Index Existential transcendence</td>
<td>Internal consistency: $\alpha = 0.77$ to 0.91 Test–retest reliability: (4–6 weeks) $r = 0.77$ to 0.90</td>
<td>+</td>
<td>?</td>
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<tr>
<td>LEQ (Salmon et al., 1996)</td>
<td>self-report</td>
<td>61</td>
<td>7-point scale with opposing items at end of each scale (0–6) Scoring not specified</td>
<td>Freedom $\alpha = 0.70$ Range 0–60 Appreciation of life, $\alpha = 0.76$ Range 0–48 Contentment $\alpha = 0.76$ Range 0–54 Resentment $\alpha = 0.85$ Range 0–78 Social integration $\alpha = 0.78$ Range 0–48</td>
<td>Test–retest reliability $(n = 40; 48–72$ hrs) $r = 0.77$ to 0.92</td>
<td>?</td>
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### Table 4. Continued

<table>
<thead>
<tr>
<th>Construct Measured</th>
<th>Tool</th>
<th>Description</th>
<th>Cancer Validation*</th>
<th>Domains</th>
<th>Reliability</th>
<th>Construct Validity</th>
<th>Responsiveness to Change (+/-)**</th>
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<tbody>
<tr>
<td>“Meaning in Life questions (Tomich &amp; Helgeson, 2002)”</td>
<td>Administration: self-report</td>
<td>Items: 20</td>
<td>164 breast cancer survivors and 164 age-matched controls</td>
<td>United States</td>
<td>Search for meaning</td>
<td>Internal consistency: (a = 0.86) to (0.89) for personal growth and acceptance (used in subsequent research as the “Benefit Finding Scale”)</td>
<td>+ (Antoni et al., 2001; Chandwani et al., 2010; Penedo et al., 2006)</td>
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<td>“MLQ (Steger et al., 2006)”</td>
<td>Administration: self-report</td>
<td>Items: 10</td>
<td></td>
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<td>Presence</td>
<td></td>
<td>+</td>
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<tr>
<td>“MiLS (Jim et al., 2006)”</td>
<td>Administration: self-report</td>
<td>Items: 21</td>
<td>167 survivors of breast cancer at least 2 years post-diagnosis (a); 384 survivors of mixed cancers recruited via the internet (b)</td>
<td></td>
<td>Harmony and peace (4 items)</td>
<td>Internal consistency: (a = 0.93)</td>
<td>?</td>
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<td>“MIST (Starck, 1983)”</td>
<td>Administration: self-report</td>
<td>Items: 20</td>
<td>Subjective characteristics of suffering (6 items)</td>
<td></td>
<td></td>
<td>(\text{Total: } a = 0.81) to 0.83</td>
<td>+ (Melton &amp; Schulenberg, 2008) ?</td>
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<tr>
<td>Scale</td>
<td>Administration</td>
<td>Items</td>
<td>Response scale</td>
<td>Subscales varied from</td>
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<tr>
<td>PMCPI (Chen, 1999)</td>
<td>Self-report</td>
<td>27</td>
<td>5-pt (1 = this is not like my thought at all to 5 = this is exactly my thought)</td>
<td>α = 0.72 to 0.81</td>
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<td>Loss (5 items)</td>
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<td>Threat (5 items)</td>
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<td>Challenge (4 items)</td>
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<td>Blame others (4 items)</td>
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<td>Blame self (4 items)</td>
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<td>Spiritual awareness (5 items)</td>
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<td>Test-retest reliability</td>
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<td>r = 0.85</td>
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<td>Personal Meaning Profile (Wong, 1998)</td>
<td>Self-report</td>
<td>57</td>
<td>7-pt (1 = not at all to 7 = a great deal)</td>
<td>Religion (9 items)</td>
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<td>Achievement (16 items)</td>
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<td>Relationship (9 items)</td>
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<td>Self-transcendence (8 items)</td>
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<td>Self-acceptance (6 items)</td>
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<td>Intimacy (5 items)</td>
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<td>Fair treatment (4 items)</td>
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<td>Test-retest reliability</td>
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<td>r = 0.85</td>
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<td>Positive Meaning and Vulnerability Scale (Bower et al., 2005)</td>
<td>Self-report</td>
<td>11</td>
<td>5-pt (0 = not at all to 4 = very much)</td>
<td>Initial factor analysis on T1 scores of 828 disease-free breast cancer survivors; confirmatory factor analysis on T1 scores of 1088 disease-free breast cancer survivors; 763 disease-free breast cancer survivors completed questionnaires at both T1 and T2 (on average 2.8 years later)</td>
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<td>Positive meaning (6 items)</td>
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<td>α = 0.84</td>
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<td>α = 0.81 to 0.83</td>
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<td>PIL (Crumbaugh &amp; Maholick, 1964)</td>
<td>Self-report</td>
<td>20</td>
<td>7-pt</td>
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<td>r = 0.81 (Spearman–Brown corrected to 0.90)</td>
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<td>α = 0.86 to 0.97</td>
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<td>(Ferrell et al., 1995)</td>
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<td>Split-half reliabilities:</td>
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<td>r = 0.77 to 0.85</td>
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<td>(Spearman–Brown corrected to 0.87 and 0.92, respectively)</td>
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<td>(Ferrell et al., 1995)</td>
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<td>Test–retest reliabilities:</td>
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<td>From 0.60 to 0.83 (1, 6, 8, and 12 week intervals)</td>
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<td>(Ferrell et al., 1995)</td>
<td>?</td>
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<tr>
<td>Construct Measured Tool Description</td>
<td>Cancer Validation*</td>
<td>Domains</td>
<td>Reliability</td>
<td>Construct Validity (+/–**)</td>
<td>Responsiveness to Change (+/–**)</td>
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<td><strong>PUB (Passik et al., 2003)</strong></td>
<td>Administration: self-report</td>
<td>100 cancer patients with mixed cancer types United States</td>
<td>Internal consistency: $\alpha = 0.84$</td>
<td>+</td>
<td>?</td>
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<td></td>
<td>Items: 14</td>
<td>Overt boredom (8 items) $\alpha = 0.93$</td>
<td>Test–retest reliability ($n = 20$, 7 days): $r = 0.80$</td>
<td>+</td>
<td>?</td>
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<td></td>
<td>Response scale: 4 pt (1 = none of the time to 4 = all of the time) Range: 14–56</td>
<td>Boredom related to meaning and spirituality (6 items) $\alpha = 0.85$</td>
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<tr>
<td><strong>SMiLE (Fegg et al., 2008)</strong></td>
<td>Administration: self-report</td>
<td>599 students in Munich and Dublin and 75 palliative care patients in Munich (majority cancer). Germany, Ireland</td>
<td>Test–retest (7 days): $\alpha = 0.71$</td>
<td>+</td>
<td>?</td>
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<td></td>
<td>Items: 3–7 self-nominated areas providing meaning to life rated for current importance and satisfaction Response scale: 7-pt; satisfaction $(-3 = \text{very unsatisfied to } 3 = \text{very satisfied})$; importance $0 = \text{not important to } 7 = \text{extremely important}$ Scores: indices of total weighting (IoW, 20–100), total satisfaction (IoS, 0–100); total weighted satisfaction (IoWS, 0–100)</td>
<td>Respondent-nominated satisfaction $\alpha = 0.71$</td>
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<tr>
<td><strong>Sense of Coherence Scale (Orientation to Life Questionnaire) (Antonovsky, 1993)</strong></td>
<td>Administration: self-report</td>
<td>Comprehensibility (11 items) $\alpha = 0.82–0.95$</td>
<td>Internal consistency:</td>
<td>+</td>
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<td>Items: 29</td>
<td>Manageability (10 items) $\alpha = 0.74–0.91$</td>
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<td>(13-item version also available) Response scale: 7-pt semantic differential (different anchors for each question) Range: 13–91 (SOC–13) 29–203 (SOC–29)</td>
<td>Meaningfulness (8 items)</td>
<td>Test–retest: $r = 0.41–0.91$ (2 weeks to 2 years)</td>
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<td>Some evidence of responsiveness to change from studies evaluating interventions (Delbar &amp; Benor Dan, 2001; Henderson et al., 2012)</td>
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</table>

*Domains: Respondence to change, Response to Change

**Construct Validity (+/–**) **

**Responsiveness to Change (+/–**) **
**SOMP and SOMP–R**

*Reker, 1996*

Administration: self-report
Items: 17
Response scale: 7-pt (not at all meaningful to extremely meaningful)
Range: Total “Breadth” score (number of items scored at greater than or equal to 5)

- **Self-transcendence**
- **Collectivism**
- **Individualism**
- **Self-preoccupation**

Internal consistency: $\alpha = 0.71$ to 0.80
Test–retest reliability:
(3 month) $r = 0.70$

**World Assumptions Scale** *(Janoff-Bulman, 1989)*

Administration: self-report
Items: 32
Response scale: 8-pt (disagree completely to agree completely)
Subsequent work also done with 6-pt scale (strongly agree to strongly disagree)
Range: scores totaled for each subscale

- **Justice**
- **Controllability**
- **Randomness**
- **Self-worth**
- **Self-controllability**
- **Luck**
- Benevolence of people and benevolence of the impersonal world (emerged as one factor rather than two)

Subscale reliabilities between 0.66 and 0.78

**Spiritual Well-Being**

Are you at peace?
Single item *(Steinhauser et al., 2006)*

Administration: self-report
Items: 1
Response scale: 5-point

248 patients with advanced serious illness (56% cancer)

Single question
$\alpha = n/a$
No test–retest reliability reported

**FACIT–Sp** *(Peterman, et al., 2002)*

3-factor (Canada et al., 2008)

Administration: self-report
Items: 12
Response scale: 5-point (0 = not at all to 4 = very)

1,167 patients (83% with cancer) (a)
240 long-term female cancer survivors (b)
8805 cancer survivors (c), United States

- **Sense of meaning**
- **Sense of peace**
- **Role of faith in illness**

$\alpha = 0.87$ (a)
$\alpha = 0.85$ (b)
$\alpha = 0.88$ (c)

+ e.g., Axelsson & Sjoden, 1999; Byock & Merriman, 1998; Henoch et al., 2010; Selman et al., 2011

**JAREL** *(Hungelmann et al., 1996)*

Administration: self-report
Items = 21
Response scale: 6-point (strongly agree to strongly disagree)

- **Faith/belief**
- **Life/self-responsibility**
- **Life-satisfaction/self-actualization**

Internal consistency: $\alpha = 0.85$

**LASA** *(Johnson et al., 2007)*

(a) *(Locke et al., 2007)*

Administration: self-report
Items: 1
Response scale: 100-mm line from 0 = as bad as it can be to 10 = as good as it can be

(a) 103 patients with advanced cancer receiving radiation therapy, United States
(b) 205 patients with newly diagnosed high-grade glioma, United States

Single item
Test–retest not reported
Internal consistency: $n/a$
<table>
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<tr>
<th>Construct Measured</th>
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<th>Construct Validity (+/−)</th>
<th>Responsiveness to Change (+/−)</th>
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<tbody>
<tr>
<td>&quot;</td>
<td>PEACE (Mack et al., 2008)</td>
<td>Administration: self-report Items: 12 Response scale: 4-point (1 = not at all to 4 = to a large extent)</td>
<td>160 patients with advanced cancer and failure of first-line chemo United States</td>
<td>Struggle with illness Peaceful acceptance</td>
<td>Internal consistency: Subscale 1: α = 0.81 Subscale 2: α = 0.78</td>
<td>+</td>
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<td>&quot;</td>
<td>STS (a) (Reed, 1991) (b) (Thomas et al., 2010)</td>
<td>Administration: self-report Items: 15 Response scale: 4-point (1 = not at all to 4 = very much)</td>
<td>55 older adult cancer patients (a) 87 women diagnosed with breast cancer in the last 5 years (b) United States</td>
<td>Single domain</td>
<td>Internal consistency: α = 0.8 to 0.93</td>
<td>+</td>
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<td>&quot;</td>
<td>Spirit 8 (Selman et al., 2012)</td>
<td>Administration: self-report Items: 8 Response scale = 5-point (1 = worst to 5 = best)</td>
<td>285 palliative care patients, 18% cancer Africa</td>
<td>Single domain</td>
<td>Internal consistency: α = 0.73</td>
<td>?</td>
<td>?</td>
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<td>&quot;</td>
<td>SHI (Highfield, 1992)</td>
<td>Administration: self-report form Nurse report form Items: 31 Response scale: 5-point (1 = never to 5 = all of the time)</td>
<td>23 patients with primary lung cancer and 27 registered nurses caring for them in 2 religiously affiliated hospitals United States</td>
<td>Spiritual needs for: Self-acceptance Relationships Hope</td>
<td>Internal consistency: Patient form: α = 0.77 Nurse form: α = 0.89</td>
<td>?</td>
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<td>&quot;</td>
<td>SPS (Reed, 1987)</td>
<td>Administration: self-report Items: 10 Response scale: 6-point (response options vary between items)</td>
<td>100 terminally ill hospitalized cancer patients United States</td>
<td>Single domain</td>
<td>Internal consistency: α = 0.93–0.95 across groups</td>
<td>+</td>
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<td>&quot;</td>
<td>STM (Leung et al., 2006)</td>
<td>Administration: self-report Items: 22 Response scale: 5-point (5 = highly satisfied to 1 = highly unsatisfied)</td>
<td>37 terminal cancer patients admitted to hospices Taiwan</td>
<td>Situational transcendence Moral transcendence Religious transcendence</td>
<td>Internal consistency: α = 0.95</td>
<td>+</td>
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<td>&quot;</td>
<td>SWBS (a) (Ellison, 1983) (b) (Sherman et al., 2005)</td>
<td>Administration: self-report Items: 20 Response scale: 6-point (strongly agree to strongly disagree)</td>
<td>(b) 38 patients with advanced cancer and 38 caregivers Also in this sample were 63 patients with advanced AIDS patients and 43 of their caregivers, reported separately</td>
<td>Religious well-being Existential well-being United States</td>
<td>(a) Internal consistency: α = 0.89 (SWB) α = 0.87 (EWB) Test–retest reliability: r = 0.93 (RWB) r = 0.86 (EVB) (b) Internal consistency: Patients α = 0.96 (RWB) α = 0.78 (EVB) Carers α = 0.96 (RWB) α = 0.81 (EVB)</td>
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<td>Multi-dimensional measures of quality of life including a spiritual/existential dimension</td>
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| HQLI (McMillan & Weitzner, 1998) | The HQLI was developed specifically for hospice patients to measure quality of life. It has a combined social/spiritual well-being subscale. Administration: self-report Items: 8 items in subscale Response options: 0–10 scale | 294 patients with cancer in hospices 32 healthy adults. United States | Single domain (8 items) | Internal consistency: $\alpha = 0.82$ | + | ? |

| LTQL (Wyatt et al., 1996) | Developed to measure QoL in long-term female cancer survivors. The LTQL has a spiritual/philosophical subscale. Administration: self-report Items: 8 items in subscale Response scale: 5-point Likert-type scale (0 = not at all, 4 = very much) | 187 female cancer survivors recruited through the tumor registry. United States | Single domain: Spiritual/philosophical | Internal consistency: $\alpha = 0.87$ | + | ? |

| MQoL (Cohen et al., 1996; 1997) | Administration: self-report Total: 16 items plus 1 global item Existential well-being subscale: 6 items Response scale: 0 = not at all to 10 = extremely | 247 oncology day centre patients. Canada (Cohen et al., 1996) 143 inpatients and outpatients from palliative care services. Canada (Cohen et al., 1997) | Physical symptoms Psychological symptoms Existential well-being Support | Internal consistency: Total: $\alpha = 0.83–0.89$ (Cohen et al., 1996; 1997) Existential: $\alpha = 0.78–0.87$ (Cohen et al., 1996; 1997) Test–retest reliability: Total: $r = 0.75$ (Cohen & Mount, 2000) Existential: $r = 0.76$ (Cohen & Mount, 2000) | + (Cohen et al., 1996; 1997) + (Cohen & Mount, 2000) |

<p>| QHAL–EC (Lo et al., 2011) | Developed to measure QoL in populations near to the end of life Administration: self-report Items: Prep for EoL = 5 items Completion = 7 items Response scale: 5-item Likert-type scale | 464 patients with advanced cancer from 24 outpatient oncology clinics. Canada | Two domains: Preparation for end of life Life completion | Internal consistency: Preparation for end of life: $\alpha = 0.73$ Life completion: $\alpha = 0.83$ | + | ? |
| Construct Measured Tool | Description | Cancer Validation* | Domains | Reliability | Construct Validity (+/?) - ** Responsiveness to Change (+/?) - ** |
|------------------------|-------------|---------------------|---------|-------------|-----------------------------------------------|-----------------|
| &quot; QoLC–E (Pang et al., 2005) | Developed as a measure of QoL of Hong Kong Chinese patients with advanced chronic disease 41 metastatic cancer patients, Hong Kong | Two domains: Value of life (6 items) and existential distress (3 items) | Internal consistency: Value of life: $\alpha = 0.83$ Existential distress: $\alpha = 0.79$ | + | ? |
| &quot; QoL–CS (Ferrell et al., 1995) | Administration: self-report Total: 41 items Spiritual subscale: 7 items Response scale: Ordinal scale 686 members of the National Coalition for Cancer Survivorship (NCCS), United States | Four domains: Physical Psychological Social Spiritual | Internal consistency: total: $\alpha = 0.93$ spiritual: $\alpha = 0.71$ Test–retest reliability (two weeks): total: $r = 0.89$ spiritual: $r = 0.90$ | + | ? |
| &quot; QoL generic version (Ferrans &amp; Powers, 1985; Ferrans et al., 1992) (QLI – CV) (Ferrans, 1990) | Administration: self-report Total: 32 items Psychological/spiritual: 7 items Response scale: 6 points Part I: (1 = very dissatisfied 6 = very satisfied) Part II: (1 = very unimportant 6 = very important) 111 breast cancer patients, United States (Ferrans, 1990) | Four domains: Health and functioning Socioeconomic/ psychological/spiritual Family Psychological/spiritual domain | Internal consistency: Total QLI: $\alpha = 0.90–0.95$ Psychological/spiritual domain Internal consistency: $(\alpha = 0.90–0.93)$ Test–retest reliability (2 weeks): Total QLI: $r = 0.81–0.87$ | + (Ferrans, 1990; Ferrans &amp; Powers, 1985; 1992) Test–retest reliability not specified (Ferrans &amp; Powers, 1992) | ? |
| &quot; SElt–M (van Wegberget al., 1998) | Developed to add a spiritual dimension to an existing quality of life measure, Administration: self-report Items: 8 items in subscale Response scale: 5 point (0 = not at all to 4 = entirely so) 89 patients with metastatic, locally advanced or nonresectable breast (n = 49) or gastro-intestinal (n = 40) cancer, Switzerland | Single domain | Internal consistency: $\alpha = 0.73$ | + | ? |</p>
<table>
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<tr>
<th>Scale</th>
<th>Description</th>
<th>Sample size</th>
<th>Administration</th>
<th>Response scale</th>
<th>Scores</th>
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<tr>
<td>WHOQoL–100 SRPB subscale</td>
<td>Developed as an overarching measure of quality of life, the WHOQoL–100 covers 24 facets of quality of life. The SRPB scale was developed to fully measure spiritual issues.</td>
<td>(a) 356 women with breast abnormality (b) 140 breast cancer survivors</td>
<td>Administration: self-report</td>
<td>Items: 32 Response scale: 5-point Likert-type scale</td>
<td>Eight factors with four items in each: spiritual connection, meaning in life, wholeness and integration, spiritual strength, inner peace, hope and optimism and faith.</td>
<td>Internal consistency: $\alpha = 0.91$</td>
<td>+? ?</td>
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<tr>
<td>ELQ (Mayers et al., 2002)</td>
<td>Spiritual pain, distress and struggle</td>
<td></td>
<td>Administration: self-report</td>
<td>Items: 22 Response scale: 6-point scale (1 = not at all true of me, 3 = sometimes true of me, 6 = very much true of me)</td>
<td>Scores: range 22–132</td>
<td>Internal consistency: $\alpha = 0.90$</td>
<td>+ ?</td>
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<tr>
<td>SDS [Taiwan] (Ku et al., 2010)</td>
<td>Distress in palliative care</td>
<td>85 cancer patients. Taiwan</td>
<td>Administration: self-report</td>
<td>Items: 30 Response scale: 4-point scale (1–4) Scores: range 30–120 Higher scores indicative of a higher level of spiritual distress</td>
<td>Relations with self Relations with others Relations with God Attitude toward death</td>
<td>Internal consistency: Total scale $\alpha = 0.95$ Relations with self $\alpha = 0.93$ Relations with others: $\alpha = 0.92$ Relations with God: $\alpha = 0.90$ Attitude toward death: $\alpha = 0.95$</td>
<td>? ?</td>
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<td>SAHD (Rosenfeld et al., 1999; 2000)</td>
<td></td>
<td>92 terminally ill cancer patients (life expectancy &lt;6 months). USA (Rosenfeld et al., 2000)</td>
<td>Administration: self-report</td>
<td>Items: 20 Response scale: true/false Scores: range 0–20 Higher scores indicative of a higher level of desire for death</td>
<td>Internal consistency: Total scale $\alpha = 0.89$ (Rosenfeld et al., 2000) Internal consistency: $\alpha = 0.88$ (Rosenfeld et al., 2000) Split-half reliability: 0.89</td>
<td>+ (Rosenfeld et al., 2000; 1999) ?</td>
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<tr>
<td>Construct Measured</td>
<td>Tool</td>
<td>Description</td>
<td>Cancer Validation*</td>
<td>Domains</td>
<td>Reliability</td>
<td>Construct Validity (+/?/−)**</td>
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<td>&quot;</td>
<td>SISC (Wilson et al., 2004)</td>
<td>Administration: clinician administered Items: 1 Response scale: 7-point ( (0 = \text{none to } 6 = \text{extreme}) ) 1 or 2 indicates the experience of the symptom or concern is relatively low. 3 corresponds to an issue that is generally a significant problem. Higher scores associated with clear presence of symptom/concern at clinically important level—varying degrees of severity.</td>
<td>69 palliative care (advanced) cancer patients. Canada</td>
<td>Single item</td>
<td>Interrater reliability: ( r = 0.99 ) Test–retest (1–3 days): ( r = 0.90 )</td>
<td>+</td>
<td>Not specified</td>
</tr>
</tbody>
</table>

*Key cancer validation sample (where applicable) reference and details listed. + = Bulk of the available evidence supportive of construct validity/responsiveness to change of the instrument, − = bulk of available evidence does not support this property, ? = this property has not been assessed or contradictory results.
Construct validity of the scale has been assessed in the context of dementia through correlations with comfort assessment in dying with dementia, but information on validity in the context of cancer is lacking at present. The scale appears responsive to change in the context of cancer, making it a potentially useful tool for monitoring patients and exploring the impact of interventions over time.

Clinician administration is both a strength and a limitation of this measure. It allows consistent assessment of all patients at the end of life, taking into account communication difficulties and avoiding burdening patients. However, clinician administration may also result in biased assessments, especially if clinicians responsible for the care of patients over time overestimate the impact of treatment.

**Pictorial Representation of Illness and Self Measure (PRISM, PRISM–R1 and PRISM–R2)**

The PRISM was originally intended as a measure of adjustment to illness, but qualitative analyses of content validity suggested its applicability as a measure of suffering (Büchi et al., 1998). The advantages of this measure include its brevity, simplicity, and ease of use (Büchi et al., 1998). In addition, by not specifying items and domains, it allows for a more subjective assessment of suffering due to illness, however patients might individually define this (Wouters et al., 2011; Wouters et al., 2008). Content validity has been explored in a number of qualitative studies (Büchi et al., 2002; Wouters et al., 2008), and there is evidence for reliability and validity (Büchi et al., 2002), although the lack of a gold-standard measure of suffering means that considerable work is necessary to satisfactorily validate this measure (Büchi et al., 2002). There are two revised versions of the measure, the PRISM–R1 and PRISM–R2 (Wouters et al., 2011), which provide additional information about the perceived severity of illness and incorporate a slightly revised response format.

The PRISM–R2 has been employed in the context of cancer survivorship, and evidence on the validity of the measure in this context has been presented (Wouters et al., 2011). The PRISM and its variants have been administered both face to face (Büchi et al., 2002; 1998; Wouters et al., 2008) and via mail (Wouters et al., 2011; Wouters et al., 2008), although it has been suggested that people with lower levels of education experienced some problems completing this more abstract measure, and face-to-face administration may be preferable (Wouters et al., 2011). The scale’s developers also raise the possibility of administering the measure via computer (Büchi et al., 1998).

Considerable work has been done exploring the psychometric properties of the PRISM, and it shows some promise as a more subjective measure of suffering, perhaps especially in the context of face-to-face clinical work. Care should be taken in determining an appropriate mode of administration, and more work on definitional validity is recommended.

**Recommendation**

The PRISM has more evidence of validity and reliability than the MSSE, though more definitional clarity is required. Furthermore, it allows a nondirective approach and provides a quantitative score for serial assessment.

A single “Are you at peace?” item (Steinhauser et al., 2006) was identified as a measure of spiritual well-being and its validity assessed against other measures of spiritual well-being (see below). However, the authors referred to it as not only a measure of spiritual well-being but also a way of identifying suffering, so this measure should also be considered in the context of measures of suffering. Peace is one of the constructs measured by the FACIT–Sp (see below) in its three-factor version (Canada et al., 2008; Murphy et al., 2010) and could also be considered in this context.

**Hopelessness/Demoralization**

Seven instruments measuring hopelessness/demoralization were identified: the Beck Hopelessness Scale (BHS) (Beck et al., 1974); the despair subscale of the Cancer Care Monitor (CCM) (Fortner et al., 2003); Jacobsen et al.’s Demoralization Scale (Jacobsen et al., 2006); Kissane et al.’s (2004) Demoralization Scale; the Hopelessness Assessment in Illness (HAI) Questionnaire (Rosenfeld et al., 2011); a clinician-administered single-item screening instrument for hopelessness (Wilson et al., 2004); and the Subjective Incompetence Scale (SIS) (Cockram et al., 2009). The HAI and Kissane et al.’s Demoralization Scale are the most promising for assessing hopelessness and demoralization, respectively, in the advanced cancer context. Both, however, are relatively new measures and require further exploration of their psychometric properties. Other tools may be optimal depending on the research question.

**Hope**

Five measures assessing hope were identified. These included the Adult Dispositional Hope Scale (ADHS) (Snyder et al., 1991); the Herth Hope Scale (HHS)/Herth Hope Index (HHI) (Herth, 1991; 1992); the Hope Differential (HD)/Hope Differential–Short (HDS) (Nekolaichuk & Brueru, 2004; Nekolaichuk et al., 1999); Miller’s Hope Scale (MHS) (Miller & Powers, 1988); and the Nowotny Hope Scale (NHS).
(Nowotny, 1989). Based on its brevity, frequency of use, and the availability of validation data in the cancer context, the HHI is optimal as a measure of hope. Note that all the measures listed have relatively high levels of internal consistency, implying that some items may be redundant.

**Meaning**

Some 20 scales were identified that measured meaning: the Chinese Cancer Coherence Scale (CCCS) (Chan et al., 2007); the Constructed Meaning Scale (Fife, 1995); the meaning/peace subscale of the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT–Sp) (Canada et al., 2008; Murphy et al., 2010; Peterman et al., 2002); the Illness Cognitions Questionnaire (ICQ) (Everson et al., 2001); the Internal Coherence Scale (ICS) (Kroz et al., 2009); the Life Attitude Profile (LAP)/Life Attitude Profile–Revised (LAP–R) (Reker, 1992; Reker & Peacock, 1981); the Life Evaluation Questionnaire (LEQ) (Salmon et al., 1996); the Meaning in Life questions (including the Benefit Finding Scale [BFS]) used by Tomich and Helgeson (2002); the Meaning in Life Questionnaire (MLQ) (Steger et al., 2006); the Meaning in Life Scale (MILS) (Jim et al., 2006); the Meaning in Suffering Test (MIST) (Starck, 1983); the Perceived Meanings of Cancer Pain Inventory (PMCLI) (Chen, 1999); the Personal Meaning Profile (PMP) (Wong, 1998); the Positive Meaning and Vulnerability Scale (Bower et al., 2005); the Purpose in Life (PIL) Test (Crumbaugh & Maholick, 1964); the Purposelessness, Understimulation, and Boredom (PUB) Scale (Passik et al., 2003); the Schedule for Meaning in Life Evaluation (SMiLE) (Fegg et al., 2008); the Sense of Coherence (SOC) Scale (Antonovsky, 1993); the Sources of Meaning Profile (SOMP)/Sources of Meaning Profile–Revised (SOMP–R) (Reker, 1996); and the World Assumptions Scale (Janoff-Bulman, 1989). The optimal measure of meaning will vary depending on the purpose and context of the assessment. However, for assessing the spiritual dimension of global meaning, the FACIT–Sp should be considered optimal, and the LAP–R should be considered a strong candidate when exploring the relationship between global meaning and other variables. Optimal measures for assessing situational meaning will vary depending on the specific context and the construct to be assessed.

**Spiritual Well-Being**

A total of 11 measures assessing spiritual well-being were identified. These included a short “Are you at peace?” item (Steinhauser et al., 2006); the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT–Sp) (Canada et al., 2008; Murphy et al., 2010; Peterman et al., 2002); the JAREL Spiritual Well-Being Scale (Hunselmann et al., 1996); a Linear Analogue Self-Assessment (LASA) item for spiritual well-being (Johnson et al., 2007; Locke et al., 2007); the Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) Scale (Mack et al., 2008); the Self-Transcendence Scale (STS) (Reed, 1991; Thomas et al., 2010); the Spirit 8 (Selman et al., 2012); the Spiritual Health Inventory (SHI) (Highfield, 1992); the Spiritual Perspective Scale (SPS) (Reed, 1987); the Spirituality Transcendence Measure (STM) (Leung et al., 2006); and the Spiritual Well-Being Scale (SWBS) (Ellison, 1983; Sherman et al., 2005). The FACIT–Sp may be optimal for assessing spiritual well-being in the cancer context. Its advantages include its development and validation in a large cancer population, its brevity, the frequency with which it is used in the context of cancer, and the substantive data available about its psychometric properties and to facilitate interpretation.

**Quality of Life**

Nine multidimensional measures of quality of life that included a spiritual/existential dimension were identified. These included the Hospice Quality of Life Index (HQLI) (McMillan & Weitzner, 1998); the Long-Term Quality of Life (LTQL) instrument (Wyatt et al., 1996); the McGill Quality of Life (MQoL) Questionnaire (Cohen et al., 1997; 1996); the Quality of Life at the End of Life–Cancer (QUAL–EC) Scale (Lo et al., 2011); the Quality of Life Concerns in the End of Life (QoLC–E) Scale (Samantha et al., 2005); the Quality of Life for Cancer Survivors (QoL–CS) Scale (Ferrrell, 1996); the Quality of Life Index (QLI)/Quality of Life Index–Cancer Version (QLI–CV) (Ferrans, 1990; Ferrans & Powers, 1985, 1992); the Skalen zur Erfassung von Lebensqualität bei Tumorkranken–Modified Version (SELT–M) (van Wegberg et al., 1998); and the World Health Organization’s Quality of Life Measure (WHOQoL–100) Spirituality/Religion/Personal Beliefs (SRPB) subscale (den Oudsten et al., 2009; WHOQoL, 2006). For multidimensional quality-of-life measurement incorporating an existential or spiritual domain, the MQoL questionnaire or FACIT–Sp appear optimal because substantive data are available about psychometric properties and interpretation in the cancer context.

**Distress in the Palliative Care Setting**

Two measures specifically assessing distress in the palliative care setting were identified: a clinician-administered single-item screening instrument for
assessing desire for death, the Structured Interview for Symptoms and Concerns (SISC) (Wilson et al., 2004), and the Schedule of Attitudes toward Hastened Death (SAHD) (Rosenfeld et al., 2011; 1999). The latter questionnaire appears promising for assessing desire for death in the context of advanced cancer, though further validation in a larger sample is recommended.

Pain, Distress, or Struggle of a Spiritual Nature

Two measures assessing pain, distress, or struggle of a spiritual nature were identified: the Existential Loneliness Questionnaire (ELQ) (Mayers et al., 2002) and the Spiritual Distress Scale (SDS) (Ku et al., 2010). Further research validating these measures in larger cancer samples is necessary before either of these measures can be recommended.

DISCUSSION

Our review revealed that a number of instruments are suitable for measuring the various analogues of suffering but that challenges remain in this field, in part as a function of the complexity of suffering itself. Definitions of suffering and clear articulation of the aspects of suffering targeted by individual measures are essential. The multidimensional and individual nature of suffering should be taken into account when considering its assessment, as should its variance dependent on culture and context (Cassell, 1982; Wein, 2011). Many authors have noted the importance of context, including cultural, historical, and social factors that impact on the meaning of an individual gives to an experience (Barton-Burke et al., 2008; Chio et al., 2008; Williams, 2004). Holistic assessment rather than a narrow focus on individual symptoms is recommended.

Further, it was evident from the review that information about the strengths, limitations, and psychometric properties of available measures for the specific use proposed should always be consulted when choosing an assessment tool. Such information will enable users to make an informed decision about the appropriate measure for any specific purpose, and/or may identify measures that might be further developed and assessed for validity. Lack of a gold-standard measure of suffering means that considerable work is necessary to satisfactorily validate these measures (Büchi et al., 2002).

Due to the individual nature of suffering and the manifold potential sources involved (Best et al., 2014), being able to assess both the personal elements of suffering for the patient as well as the objective would be advantageous. Measures to assess suffering may therefore be particularly useful if they include a subjective component (e.g., the PRISM, the SMiLE, the Hope Differential–Short, and the single item “Are you at peace?”); they may need to be supplemented by open questions and alertness to the nonverbal and verbal cues of the patient. Care should be taken in determining the appropriate mode of administration, and face-to-face administration would be considered preferable in populations with varying educational levels.

The distress of cancer patients who are suffering will often take a toll on their reserves that will make lengthy assessment tools burdensome in the clinical context. Further research should be conducted into the psychometric properties and usefulness of single-item measures of suffering, with potential use for clinical application as a screening tool and door-opener for discussion of patient concerns (Bayes et al., 1996). Potentially useful items include “Are you at peace?” and “How long did yesterday seem to you?” (Bayes et al., 1996).

Despite the numerous measures available for the assessment of suffering and its synonyms and symptoms, more work is needed to validate these tools in the cancer milieu. However, the wide range of assessment instruments currently under development will allow the clinician to focus on specific aspects of suffering to suit their clinical context.

LIMITATIONS

There are a number of limitations to the current review that should be acknowledged when interpreting results.

First, the search strategy adopted for our review was designed so as to allow for the synthesis of common elements across a number of concepts highlighted in the existing literature as potentially synonymous with suffering. Including existential and spiritual suffering/distress allowed due attention to be paid to an important and often overlooked dimension of suffering. The review authors believe that this broad synthesis of the common elements of these constructs enhances our understanding of the nature of suffering in the context of cancer; however, these concepts are not always seen as identical. The potentially useful nuances of each individual concept have therefore not been fully explored in this review.

Second, the search for measures focused on a list of “synonyms” and “symptoms” of suffering generated by an iterative review of the literature. This strategy allowed for the consistent inclusion of any measure targeting hope, meaning, or spiritual well-being; this appeared the most reliable and parsimonious of the possible search strategies identified.
Third, holistic care in the cancer context involves not only the patient but also the family as the unit of care. The suffering of families and carers is deserving of attention; however, feasibility constraints precluded addressing this important issue within the scope of the current review.

CONCLUSION

This report reviews research published between 1992 and 2012 to identify validated tools that measure spiritual suffering or its symptoms in cancer patients. Some 90 articles were identified that yielded information about 58 measures. The constructs examined were: suffering, hopelessness/demoralization, hope, meaning, spiritual well-being and quality of life where a spiritual/existential dimension was included, distress in the palliative care setting, and pain, distress or struggle of a spiritual nature. The psychometric properties of these measures were compared. The PRISM shows promise as a direct measure of the burden of suffering due to illness, in terms of ease of use, and the possibility of capturing individual aspects of suffering. A number of other measures with promising psychometric properties are now available to measure the particular dimensions of spiritual suffering.

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Spiritual suffering in the cancer context


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