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Spirituality at the End of Life: Conceptualization of Measurable Aspects—a Systematic Review

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Abstract

Although spiritual caregiving is a key domain of palliative care, it lacks a clear definition, which impedes both caregiving and research in this domain. The aim of this study was to conceptualize spirituality by identifying dimensions, based on instruments measuring spirituality in end-of-life populations. A systematic literature review was conducted. Literature published between 1980 and 2009, focussing on instruments measuring spirituality at the end of life was collected from the PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO databases. Inclusion criteria were: (1) the studies provide empirical data collected with an instrument measuring spirituality or aspects of spirituality at the end of life; (2) the data report on a (subgroup) of an end-of-life population, and (3) the instrument is available in the public domain. Content validity was assessed according to a consensus-based method. From the items of the instruments, three investigators independently derived dimensions of spirituality at the end of life. In 36 articles that met the inclusion criteria we identified 24 instruments. Nine instruments with adequate content validity were used to identify dimensions of spirituality. To adequately represent the items of the instruments and to describe the relationships between the dimensions, a model defining spirituality was constructed. The model distinguishes the dimensions of Spiritual Well-being (e.g., peace), Spiritual Cognitive Behavioral Context (Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships), and Spiritual Coping, and also indicates relationships between the dimensions. This model may help researchers to plan studies and to choose appropriate outcomes, and assist caregivers in planning spiritual care.

Introduction

This article conceptualizes spirituality at the end of life, which is, in addition to physical and psychosocial aspects, one of the three domains of palliative care.[1] Spiritual issues frequently become more relevant at the end of life. Moreover, patients often experience spiritual distress at the end of life, and the importance of its alleviation, as a contribution to spiritual and psychosocial well-being, has been acknowledged in various studies.[2,3] In a study of cancer patients, the existential domain was more important in determining quality of life of patients with local and metastatic diseases than that of patients with no disease.[4] In a study of 340 patients with advanced disease, most patients considered spiritual issues important. More than 80% indicated that being prepared to die, being at peace with God, praying, and feeling that one's life is complete is important at the end of life.[5] In another study in a palliative care setting, more than 90% of the patients reported that spirituality was important to them. Religious coping was associated with the physical and emotional well-being subscales of the Functional Assessment of Cancer Therapy (FACT-G), and the FACT-G total score.[6] In sum, spirituality contributes to good quality of life, which is the main goal of palliative care.[7]

Although there is a broad consensus on the importance of spiritual care at the end of life, only limited attention is paid to it in clinical practice. One explanation is a lack of consensus on the definition, or concept of spirituality at the end of life.[8–10] Definitions of spirituality that have been reported in the literature so far are only to a certain extent compatible. "Meaning" is included in many definitions, but there is a lack of consensus on other elements. Daaleman et al[11] approached

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the concept from the angle of spiritual beliefs and activities: "Those beliefs, practices and stories that respond to a shared human need for meaning," whereas Steinhauser et al.[12] defined spirituality as "The search for attention to the ultimate meaning and purpose in life, often involving a relationship with the transcendent," and focused on the construct of "being at peace." In a recent definition, Puchalski et al.[13] emphasized the importance of connectedness, whereas King and Koenig[14] emphasized the possible relationship between (aspects of) spiritual well-being and spiritual beliefs and activities. Spiritual activities such as religious rituals and possible outcomes of such activities (e.g., experience of connectedness) are used interchangeably in the various definitions. Due to lack of consensus on a clear definition, researchers and practitioners are given little guidance in assessment of spiritual needs at the end of life, which is a barrier to the provision of adequate spiritual end-of-life care.

The aim of this systematic review is to conceptualize spirituality by identifying dimensions of spirituality at the end of life, based on items of instruments measuring (aspects of) spirituality in end-of-life populations. We adopted this empirical approach because it may reconcile domains into a concept that is more useful in practice and research than what has been achieved by other, more theoretical approaches. The following two research questions were addressed: (1) Which instruments measuring aspects of spirituality in end-of-life populations are available, and what is the content validity of these instruments? (2) Which dimensions that may conceptualize spirituality can be derived from the items of these instruments?

Methods

We systematically searched the PubMed, PsycINFO, and CINAHL databases. The time frame was January 1, 1980 to August 27, 2009. The search combined three search fields: (1) palliative care/end of life, (2) spirituality, and (3) a methodological search filter to identify instrument measurement properties. These fields were searched with controlled vocabulary (MESH in case of PubMed) and free-text terms and synonyms were searched for in titles and abstracts. The Appendix includes the full search strategy. The following inclusion criteria were applied:

- Studies provide empirical data on an instrument measuring spirituality or aspects of spirituality at the end of life;
- Data exclusively report on populations or identifiable subgroups of patients with a life-threatening disease. Life-threatening disease was:
  - Advanced disease and/or otherwise a situation in which the patient will die within a short period, such as terminally ill cancer patients or patients with a life-expectancy of 6 weeks or less
  - Cancer stage IV and/or
  - Receiving palliative care (such as hospice patients, patients in a palliative care unit, or identified by a palliative consultation service)
- The instrument is available in the public domain.

In the first phase, the primary reviewer (MJG) selected potentially relevant articles based on title and abstract. To refine the selection criteria, a pilot set of abstracts was independently reviewed by two other researchers (MAE and JTS), and this resulted in standardization of the selection criteria. These criteria, when needed, were applied to the initially selected publications in an iterative process. In the second phase, the primary reviewer (MJG) retrieved and read the full texts of the selected publications. This procedure was also applied to a pilot set of articles that was independently reviewed by one other researcher (MAE). Similarly, this process resulted in standardization of the selection criteria. We decided to select not only instruments on spirituality, but also quality-of-life instruments with a subscale measuring spirituality or single items, that the authors considered spiritual items. Some quality-of-life instruments contained items that appeared to be spiritual, but were not identified or considered as such by the authors. These items of such quality-of-life instruments were not included. Ambiguous cases were discussed with MAE and JTS, until consensus was achieved. Finally, the instruments were retrieved.

After searching the literature and selecting the instruments, content validity was determined by applying the Terwee et al. criteria as part of an assessment of psychometric properties.[15] The development of the instrument received a positive score for content validity when it met the following criteria:

1. The instrument is available in the public domain (because it was one of the inclusion criteria this criterion was always met);
2. The intended measurement aim of the questionnaire, the target population, and the process of item-selection for the instrument are clearly described;
3. The target population is involved in the item-selection in combination with reference to the literature or consultation with experts.

Based on these criteria, the instruments could be scored "+," "±," "–," or "0," as follows:
positive (+)—all three criteria are met; intermediate (±)—criterion three was not met; negative (−)—criteria two and three were not met; not determined (0)—no information on content validity.
As we were interested in the content validity of instruments in end-of-life populations, we assessed whether the target population (e.g., the population in which the instrument is developed) was an end-of-life population. All the items of these instruments were studied independently by three researchers (MJG, JTS, MAE) to identify overarching aspects of spirituality at the end of life. Each of the researchers independently (1) defined the smallest possible set of categories based on the content of the instrument items, and (2) verified that all the items fitted into the categories. Subsequently, findings were discussed by three researchers (MJG, JTS, MAE) until consensus was achieved on the labelling process.

Results

The search resulted in 2900 hits: 1165 in PubMed, 1296 in CINAHL, and 439 in PsycINFO. Fig. 1 shows the process of including abstracts and full text articles. The 39 articles that met the inclusion criteria described 24 instruments measuring spirituality.

Table 1 presents the 24 instruments measuring spirituality and their content validity.[6,7,8,12,16–64] Content validity could not be determined because no information on content validity

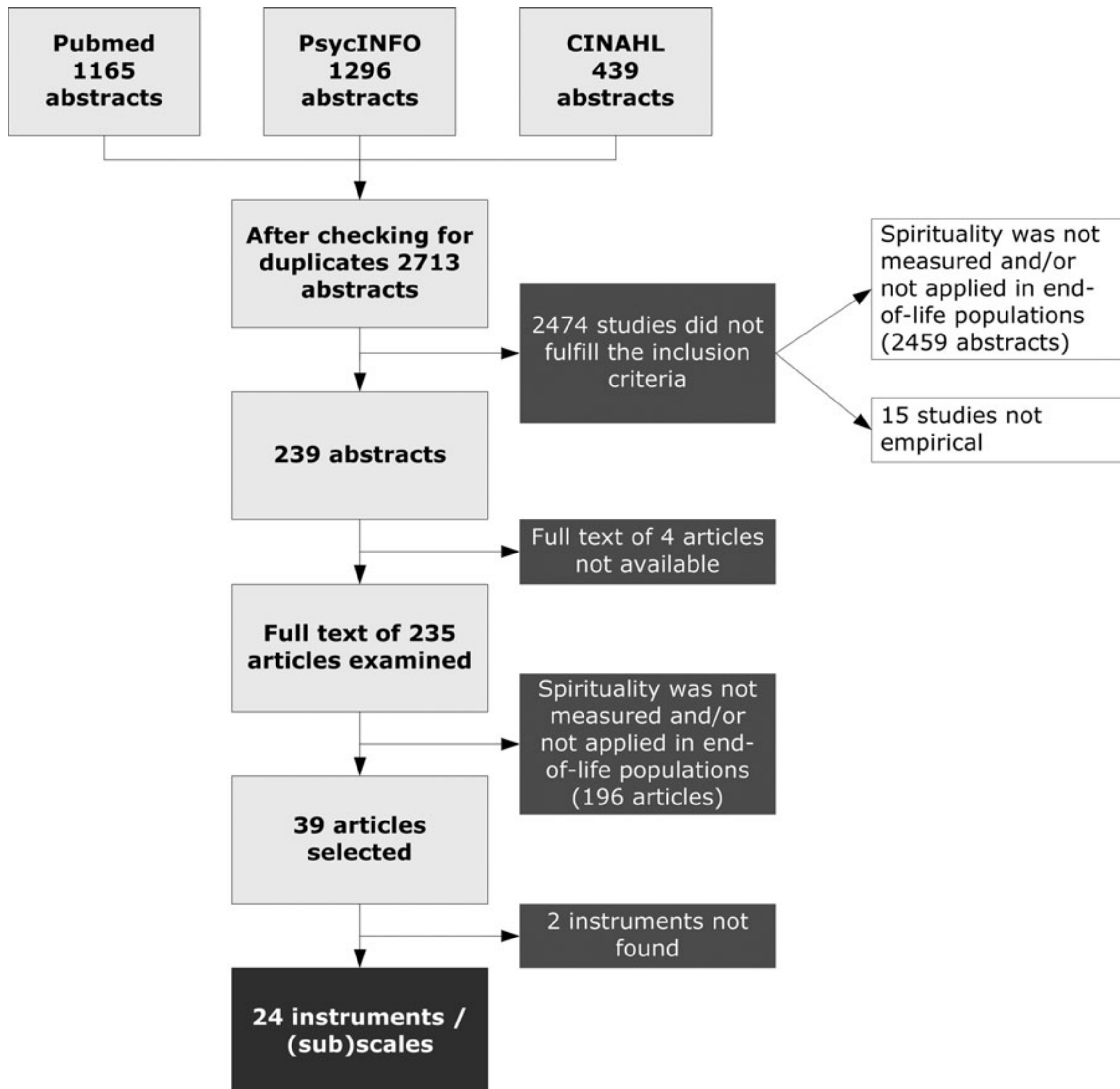

FIG. 1. Flow chart illustrating the article and instrument selection process.

was found in 5 of 24 instruments (21%). These included 3 instruments that mainly focused on religion: the FICA[6] and 2 instruments developed at the Fetzer Institute: the subscales for Forgiveness and Religious Meaning.[37] Further, we were unable to find the Spiritual Perspective Scale,[27] because reference was made to an unpublished manuscript. Finally, the Spiritual Well-being Questionnaire[48] was an adaption from the Spiritual Well-being Scale,[51] with the word "God" substituted by the word "Spirituality" and the word "today" added to each item.

Of the remaining 19 instruments (79%), 14 had a positive content validity score, 3 had an intermediate score, and 2 a negative score. The content validity of 9 instruments (38% of the total of 24 instruments) was determined in end-of-life populations. Three instruments measured spirituality: the Spiritual Needs Inventory (SNI),[24] the JAREL Spiritual Well-being Scale,[53] and "Are you at peace?'[12], whereas 6 instruments measured quality of life, with a subset of items on spirituality: the Quality of Life at the End of Life Measure (QUAL-E),[45] the Hospice Quality of Life Index,[31] the Missoula Vitas Quality of Life Index,[62] the McGill Quality of Life Questionnaire,[22] the Good Death Inventory,[33] and the Needs Assessment for Advanced Cancer Patients (NA-ACP[39]).

In the process of identifying overarching aspects of spirituality at the end of life, the three researchers independently labelled all items of the 24 instruments, comparing and discussing their results until consensus was achieved on the labelling. For instance: "I feel peaceful" was labelled "Peace" (Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; FACIT-Sp[52]); "Belief in afterlife" was labelled "Beliefs" (Spiritual Transcendence Measure[28]). Many items described different kinds of positive feelings, for example, "thankful," "feel good," "enjoyable," "having some pleasure." These were categorized as: "Positive Affect." Positive affect represented the dimension Spiritual Well-being, along with peace, harmony, trust, hope, acceptance, purpose, meaning, connectedness, completion, fulfilment, and comfort.

Within categories, there was variability in items. The items labelled "Beliefs" may refer to an inventory, for instance, "Do you have a specific religion?" (Royal Free Interview[55]),

Table 1. Identified Instruments and Content Validity

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument: Score	Content validity of the instrument: Reference
a. The 9 instruments in which content validity met the criteria and in which an end-of-life population was involved				
Spiritual Needs Inventory (SNI)	Hermann CP, 2007[25]	Hospice patients ($n=100$)	+	Hermann CP, 2006[24]
	Hermann CP, 2006[24]	Hospice patients ($n=100$)		
JAREL Spiritual Well-being Scale	Prince-Paul M, 2008[38]	Adult hospice patients ($n=50$)	+	Hungelmann J et al., 1996[53]
"Are you at peace?"	Steinhauser K et al., 2006[12]	Stage IV cancer, COPD FEV_1 <1l, CHF ejection fraction <20% ($n=248$)	+	Steinhauser K et al., 2006[12]
Quality of Life at the End of Life Measure (QUAL-E)	Steinhauser K et al., 2004[45]	Stage IV cancer, COPD FEV_1 <1l, CHF ejection fraction <20 % ($n=248$)	+	Steinhauser K et al., 2004[45]
Hospice Quality of Life Index (HQLI)	McMillan SC & Weitzner M, 1998[32]	Hospice patients with cancer ($n=255$)	+	McMillan SC, 1996[31]
	McMillan SC, 1996[31]	Home-based hospice care (n = 118)		
	McMillan SC & Mahon M, 1994[30]	Hospice patients ($n=68$)		
Missoula Vitas QOL (MVQOLI)	Willams AL et al., 2005[47]	AIDS, CD4 <200/mm^3, viral load >100.000/mL, comorbidity ($n=58$)	+	Byock IR & Merriman MP,1998[62]
	Steele LL et al., 2005[44]	Convenience sample of terminally ill patients (n = 129)		
	Schwartz CE et al., 2005[41]	Hospice patients ($n=31$)		
	Steinhauser K et al., 2004[45]	Stage IV cancer, COPD FEV_1 <1l, CHF ejection fraction <20% ($n=248$)		
McGill Quality of Life Questionaire (MQOL)	Sherman DW et al., 2005[42]	Tumor that metastasized despite chemo, radiation, or hormonal therapy, AIDS, >100.000 viral load, CD4 0-200 cells/mm^3, one or more hospital admissions in the last year ($n=101$)	+	Cohen SR & Mount BM, 2000[22]
	Bentur N & Resnizky S, 2005[19]	Advanced cancer, admitted in home hospice units ($n=100$)		
	Scobie G & Caddell C, 2005[7]	Terminally ill patients in hospices ($n=120$)		
	Tang WR et al., 2004[46]	Participants of two hospice programs ($n=60$)		
	Cohen SR & Mount BM, 2000[22]	Subset palliative home care ($n=47$)		
Good Death Inventory	Miyashita M et al., 2008[33]	Bereaved family members of cancer patients who had died ($n=189$)	+	Miyashita M et al., 2008[33]
Needs Assessment for Advanced Cancer Patients (NA-ACP)	Rainbird KJ et al., 2009 [50]	Incurable cancer with life expectancy between 3 months and 2 years ($n=246$)	+	Rainbird KJ et al., 2005[39]
	Rainbird KJ et al., 2005 [39]	Incurable cancer with life expectancy between 3 months and 2 years ($n=246$)		
b. The 15 other instruments in which an end-of-life population was not involved				
Palliative Care Outcome Scale (POS)	Bausewein C et al., 2005[18]	Hospital support team, palliative care units, hospice ($n=118$)	+	Hearn J & Higginson IJ, 1997[63]
	Brandt HE et al., 2005[20]	Life expectancy of 6 weeks or less, nursing homes ($n=448$)		
	Higginson IJ & Donaldson N, 2004[26]	Patients receiving home or hospice palliative care ($n=140$)		
	Hearn J & Higginson IJ, 1999[23]	Patients receiving palliative care ($n=148$)		
	Justo Roll I et al., 2008[49]	Advanced malignant disease with a physician's prognosis of 6 months or less ($n=91$)		
The Patient Dignity Inventory (PDI)	Chochinov H et al., 2008[21]	Patients receiving palliative care ($n=253$)	+	Chochinov H et al., 2007[64]

(*continued*)

Table 1. Continued

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument	
			Score	Reference
The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale (FACIT-Sp)	Ando M et al. 2008[17]	Cancer patients from the palliative care unit ($n = 30$)	+	Peterman AH et al., 2002[52]
	Hills J et al., 2005[6]	Patients of palliative care consult service ($n = 31$)		
	Steinhauser K et al., 2004[45]	Stage IV cancer, COPD FEV_1 <1l, CHF ejection fraction <20% ($n = 248$)		
	Nelson CJ et al., 2002[35]	Terminally ill patients diagnosed with cancer and AIDS ($n = 162$)		
Royal Free Interview	McCoubrie RC & Davies AN, 2006[29]	Metastatic or incurable cancer, hospice ($n = 85$)	+	King M et al., 2001[55]
Spiritual Involvement and Beliefs Scale (SIBS)	Mystakidou K et al., 2007[34]	Patients in a palliative care unit (n = 82)	+	Hatch RL et al., 1998[56]
Spiritual Transcendence Measure (STM)	Leung KK et al., 2006[28]	Terminal cancer patients, palliative care units ($n = 37$)	+/−	Leung KK et al., 2006[28]
Skalen zur Erfassung von Lebensqualität bei Tumorkranken, modified version (SELT-M)	Ando M et al., 2007[16]	Terminally ill cancer patients ($n = 12$)	+/−	Wegberg van B et al., 1998[54]
Fetzer Institute Subscale Daily Spiritual Experience	Park C, 2008[37]	Advanced CHF, estimated mortality rate 30%–40% annually ($n = 111$)	+/−	Underwood LG & Teresi JA, 2002[58]
Spiritual Well-being Scale (SWBS)	Ruszicka S et al., 2007[40]	Terminal cancer, "malignant with anticipated death" ($n = 50$)	−	Paloutzian RF & Ellison CW, 1982[51]
	McCoubrie RC & Davies AN, 2006[29]	Metastatic or incurable cancer, hospice ($n = 85$)		
	Sherman DW et al., 2005[42]	Advanced cancer, life expectancy less than a year, HIVRNA > 100.000, CD40-200 cells/mm^3 ($n = 101$)		
	Tang WR et al., 2004[46]	Participants of two hospice programs ($n = 60$)		
	Pace JC & Stables JL, 1997[36]	Patients from a community based hospice ($n = 55$)		
Fetzer Institute, subscale Brief RCOPE	Hills J et al., 2005[6]	Patients of palliative care consult service ($n = 31$)	−	Pargament KI et al., 2000[57]
Fetzer Institute, subscale Forgiveness, short version	Park C, 2008[37]	Advanced CHF, estimated mortality rate 30%–40% annually ($n = 111$)	0	Idler E, 2003[59]
Fetzer Institute, subscale Religious Meaning, short version	Park C, 2008[37]	Advanced CHF, estimated mortality rate 30%–40% annually ($n = 111$)	0	Pargament KI, 2003[60]
Spiritual Assessment Tool FICA	Hills J et al., 2005[6]	Patients of palliative care consult service ($n = 31$)	0	Puchalski C & Romer AL, 2000[61]
Spiritual Perspective Scale	Ita DJ, 1995[27]	Home hospice patients ($n = 69$)	0	Ita DJ, 1995[27]
Spiritual Well-being Questionnaire	Wlodarczyk N, 2007[48]	Patients in in-patient hospice unit ($n = 10$)	0	Wlodarczyk N, 2007[48]

Note: the content validity criteria (see method section):
+ All the validity criteria are met.
± All the validity criteria are met, except target population was not involved in item selection.
− Item selection was not described clearly and target population was not involved in item selection.
0 No relevant information on content validity.
CHF, congestive heart failure; COPD FEV_1, chronic obstructive pulmonary disease forced expiratory volume in 1 second.

whereas other items related to the content or meaning of beliefs to the patient: "I think about how my life is a part of a larger spiritual force" (Brief Religious Coping Scale; Brief RCOPE[57]), or referred to needs or problems concerning the Spiritual beliefs, such as "I desire to be closer to God or in union with the divine" (Daily Spiritual Experience Scale[58]). We categorized these as Spiritual Beliefs. The items labelled prayer, meditation, reading religious texts, and attending religious services were categorized as Spiritual Activities. Many items referred to "Spiritual Relationships": with people from the religious community, for example, "talk with someone about religious or spiritual issues" (Spiritual Needs Inventory[24]), relationships with loved ones, for example, "There is someone in my life with whom I can share my deepest thoughts" (QUAL-E[45]), relationship with pastor, vicar or priest, e.g. 'Being able to see your priest, chaplain or minister' (NA-ACP[39]), and relationship with God, for example, "Bargained with God to make things better" (Brief RCOPE[57]). We categorized these as Spiritual Relationships. We combined Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships into the dimension of Spiritual Cognitive Behavioral Context.

We only labelled three items as Spiritual Coping, for example, "Dealing with spiritual issues of death and dying" (NA-ACP[39]). We considered the dimension Spiritual Coping as all behavior and cognitions aimed at decreasing of perceived distress and increasing spiritual well-being by means of Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships. Ten instruments had a total of 38 items on the association between Spiritual Coping and other dimensions, 22 of these were in the Brief RCOPE.

A preliminary model was constructed and tested for comprehensiveness by fitting all items from the 9 instruments (Table 1) into the dimensions of the model, again based on the independent opinions of the reviewers, followed by a consensus procedure. A minimally revised model, presented in Fig. 2, allowed all items to fit. All identified aspects of the 9 instruments that met the criteria for content validity were completely covered by the three dimensions of Spiritual Well-being, Spiritual Cognitive Behavioral Context, and Spiritual Coping and associations between these dimensions. Moreover, we could construct the same model with the items of the 15 instruments that did not meet the criteria for content validity for reason of not being specifically developed for end-of-life populations.

Table 2 shows that the instruments varied in the number of items representing the dimensions, and their associations. Out of a total of 291 items, 94 items (32%) were related to the dimension Well-being, 46 (16%) to Beliefs, 23 (8%) to Activities, and 63 (22%) were related to Relationships. Three items (1%) were related to Spiritual Coping, and a total of 62 items (21%) represented associations between the dimensions.

Most instruments include various dimensions. The Spiritual Well-being Scale, for instance, has 10 items concerning Spiritual Well-being and 6 concerning Spiritual Relationships, 3 on the association between these dimensions and one on the association between Spiritual Well-being and Spiritual Activities (Table 2). Eight of the items of the FACIT-SP[52] are related to Spiritual Well-being, 2 to the association between Spiritual Well-being and Spiritual Beliefs, and one is related to the association between Spiritual Well-being and Spiritual Coping. The

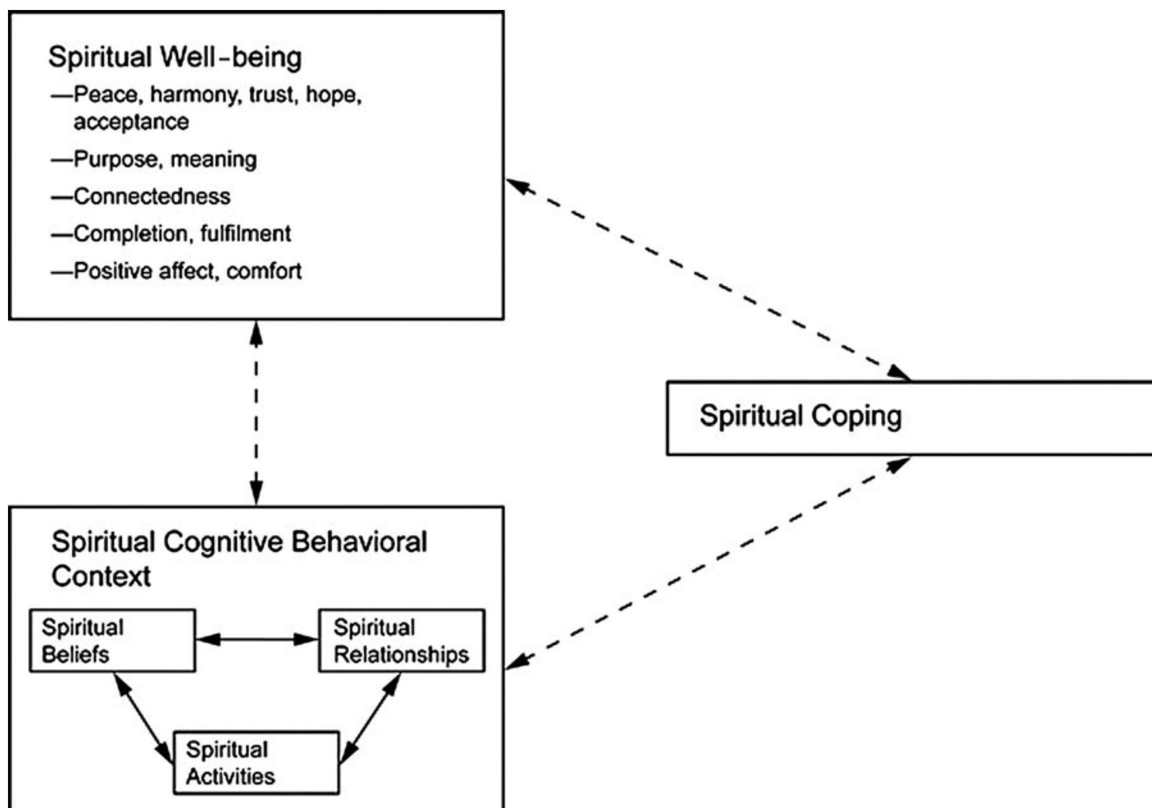

FIG. 2. A model for the conceptualization of spirituality at the end of life.

Table 2. Number of Instrument Items Representing Content of Spirituality

Instruments	Total	Well-being	Beliefs	Activities	Relationships	Coping	Content	Number
	Number of items on spirituality							
			Spiritual cognitive behavioral context				*Items indicating relationships between dimensions*	
Spiritual Needs Inventory (SNI)	16	2	–	6	8	–		
JAREL Spiritual Well-being Scale	20	7	6	1	4	–	Relationships-Spiritual Coping	1
							Spiritual Well-being-Spiritual Coping	1
“Are you at peace?”	1	1	–	–	–	–		
Quality of Life at the End of Life Measure (QUAL-E)	8	3	–	–	2	–	Spiritual Well-being- Relationships	3
Hospice Quality of Life Index (HQLI)	6	3	–	–	3	–		
Missoula Vitas Quality of Life Index (MVQOLI)	6	4	2	–	–	–		
McGill Quality of Life Questionnaire (MQOL)	7	5	1	–	1	–		
Good Death Inventory	15	7	1	–	3	–	Spiritual Well-being-Relationships	3
							Beliefs-Spiritual Coping	1
Needs Assessment for Advanced Cancer Patients (NA-ACP)	11	4	1	–	4	1	Spiritual Well-being-Spiritual Coping	1
Spiritual Well-being Scale (SWBS)	20	10	–	–	6	–	Spiritual Well-being-Relationships	3
							Spiritual Well-being-Activities	1
Spiritual Transcendence Measure (STM)	19	10	1	1	3	–	Spiritual Well-being-Activities	2
							Spiritual Well-being-Spiritual Coping	1
							Relationships-Spiritual Coping	1
The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp)	11	8	–	–	–	–	Spiritual Well-being-Beliefs	2
							Spiritual Well-being-Spiritual Coping	1
Skalen zur Erfassung von Lebensqualitat bei Tumorkranken, modified version (SELT-M)	8	5	–	–	–	1	Spiritual Well-being-Spiritual Coping	2
Royal Free Interview	13	–	9	2	1	–	Beliefs-Spiritual Coping	1
Spiritual Involvement and Beliefs Scale (SIBS)	26	3	6	8	5	1	Spiritual Well-being-Activities	2
							Spiritual Well-being-Beliefs	1
Fetzer Institute, subscale Brief RCOPE	48	–	10	2	14	–	Beliefs-Spiritual Coping	1
							Activities-Spiritual Coping	6
							Relationships-Spiritual Coping	15
Fetzer Institute, subscale Daily Spiritual Experience Scale	9	4	–	–	1	–	Spiritual Well-being-Beliefs	2
							Spiritual Well-being-Activities	1
							Activities-Spiritual Coping	1
Fetzer Institute, subscale Forgiveness, short version	3	1	1	–	1	–		
Fetzer Institute, subscale Religious Meaning, short version	2	2	–	–	–	–		
Spiritual Perspective Scale	10	–	3	3	3	–	Spiritual Well-being-Beliefs	1
Spiritual Well-being Questionnaire	13	10	1	–	1	–	Spiritual Well-being-Beliefs	1
Spiritual Assessment Tool FICA	13	–	4	–	3	–	Spiritual Well-being-Beliefs	1
							Beliefs-Spiritual Coping	2
							Relationships-Spiritual Coping	3
Palliative Care Outcome Scale (POS)	3	2	–	–	1	–		
The Patient Dignity Inventory (PDI)	3	3	–	–	–	–		

Missoula-Vitas Quality of Life Index[62] includes 4 items on Spiritual Well-being and 2 on Spiritual Beliefs. Four more items on Spiritual Well-being concerned changes caused by the illness, for example, "Thanks to my illness, I was able to make valuable experiences I would not have gained otherwise" (SELT-M[16]).

Discussion

This study aimed to conceptualize spirituality by identifying dimensions based on instruments measuring spirituality or aspects of spirituality in end-of-life populations. From 2900 hits in three databases, 39 articles and 24 instruments were identified in the literature. Fourteen instruments met the requirements for content validity, and in 9 of these instruments the content validity was assessed in an end-of-life population. The variety of instruments in the understudied domain of spirituality at the end of life was greater than we had anticipated.

From the items of these 9 instruments a conceptual model of spirituality was constructed, with the following dimensions: Spiritual Well-being, Spiritual Cognitive Behavioral Context (including Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships), Spiritual Coping, and associations between these dimensions. We did not find any instruments that focussed on satisfaction with spiritual care.

The model was based on instruments developed in end-of-life populations, and the population was involved in selection of the items combined with reference to the literature or consultation with experts. The individual instruments have therefore been developed based on theories of what constitutes spirituality. Thus the items are rooted in a variety of theories. These items, the empirically measurable aspects of spirituality, were then used to develop the model of spirituality, which therefore can be considered as an overarching concept of spirituality.

How does our model relate to previous definitions of spirituality? Vachon et al.[65] defined spirituality as "a developmental and conscious process, characterized by two movements of transcendence: either deep within the self or beyond the self." This definition was based on a conceptual analysis of definitional elements of spirituality identified by reviewing the empirical literature. Eleven different themes were listed, for example, "meaning" and "faith and beliefs," but these domains had different levels of abstraction, for example, "conscious nature" was believed to transcend all other themes. Nevertheless, the authors did not fit the elements into a conceptual or hierarchical model.[66] Puchalski et al.[11] recently published a consensus report in which they included an agreed-upon definition: "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (p. 887). This definition comprises the three dimensions of our model: Spiritual Well-being (meaning and purpose, connectedness), Spiritual Cognitive Behavioral Context (relationships with others, beliefs), and Spiritual Coping (seek and express). Our model therefore concurs with this definition. We believe that our model has additional value, in that it not only distinguishes dimensions, but also recognizes the different nature of those dimensions and their relationships, including operationalization of the dimensions.

A recent review[67] assessed spiritual items limited to 15 instruments measuring quality of life in palliative population instruments, 8 of which are included in our study. Not surprisingly, items in that study mostly related to our dimension of Spiritual Well-being. Our more inclusive review found more instruments that included religion, belief, and other contextual factors, providing a more balanced review of aspects relevant to spirituality at the end of life.

We consider the dimension Spiritual Well-being in our model as a care outcome, to which Spiritual Coping, Spiritual Activities, Spiritual Beliefs, and Spiritual Relationships can contribute. As the dimension of Spiritual Coping was found in only 3 of 24 included instruments, the importance of this dimension must be verified in further research.

Benefits of our model include that it contains only aspects that were demonstrated to be empirically viable, and were distinguished in dimensions, thus simultaneously separating content and level of abstraction. Users may wish to focus on one or two dimensions that are relevant, for instance for assessment or research. The model aims to be comprehensive, and thus covers the full scope of the concept of spirituality, which may be useful for the development or assessment of instruments. It may help in the formulation of research hypotheses (e.g., the relationships between the dimensions). The model may thus contribute to better understanding of spirituality at the end of life. Because the model could equally well be constructed from instruments developed especially for palliative care, or from more generic instruments, the model may be valid both in and beyond end-of-life situations, thus allowing study of how the model's dimensions, including their associations, vary in importance during the changing health status of the patient. Future research should test this assumption, and also the usefulness of the model in practice.

A limitation of our study is that in the process of reviewing the literature, the primary reviewer made the first selection of articles, based initially on title and abstract, and later on the full texts of the articles, although the other two researchers were involved in refining and standardizing the selection criteria.

Conclusions

A systematic review of instruments measuring spirituality that are currently being used in end-of-life situations resulted in a comprehensive model conceptualizing spirituality, and distinguishing three dimensions of spirituality and their associations. This model potentially contributes to a better understanding of spirituality at the end of life, and may also be applicable beyond end-of-life situations. It may help researchers to plan studies and choose appropriate outcomes, and assist caregivers in planning spiritual care.

Author Disclosure Statement

No conflicting financial interests exist.

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(*Appendix follows* →)

Appendix

PubMed search August 27, 2009 (read from bottom up)

No.	Query	Hits
#4	Search #1 AND #2 AND #3	1165
#3	Search "Palliative Care"[Mesh] OR palliative[tiab] OR "Terminal Care"[Mesh] OR terminal[tiab] OR "end of life"[tiab] OR "limited life"[tiab] OR "Hospice Care"[Mesh] OR palliati*[tiab] OR hospice*[tiab] OR "Aged, 80 and over"[Mesh] OR "Aged"[Mesh] OR "Chronic Disease"[Mesh] OR "Hospitals, Chronic Disease"[Mesh] OR "Attitude to Death"[Mesh] OR dying*[tiab]	2264412
#2	Search "Spiritual Therapies"[Mesh:NoExp] OR "Spirituality"[Mesh] OR spiritual*[tiab] OR religion[tiab] OR religious[tiab] OR (meaning[tiab] AND (life[tiab] OR death[tiab])) OR pastoral[tiab] OR faith[tiab]	27800
#1	Search ("Clinical Audit"[Mesh] OR audit[tiab] OR "outcome assessment (health care)"[MeSH] OR instrumentation[sh] OR Validation Studies [pt] OR "reproducibility of results"[MeSH Terms] OR reproducib*[tiab] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tiab] OR clinometr*[tiab] OR "item selection"[tiab] OR "item reduction"[tiab] OR "observer variation"[MeSH] OR observer variation[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR valid*[tiab] OR coefficient[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR "item correlation"[tiab] OR "item correlations"[tiab] OR "item selection"[tiab] OR "item selections"[tiab] OR "item reduction"[tiab] OR "item reductions"[tiab] OR agreement[tw] OR precision[tw] OR imprecision[tw] OR "precise values"[tw] OR test-retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobeserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR "coefficient of variation"[tiab] OR repeatab*[tw] OR ((replicab*[tw] OR repeated[tw]) AND (measure[tw] OR measures[tw] OR findings[tw] OR result[tw] OR results[tw] OR test[tw] OR tests[tw])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR "factor analysis"[tiab] OR "factor analyses"[tiab] OR "factor structure"[tiab] OR "factor structures"[tiab] OR dimensionality[tiab] OR subscale*[tiab] OR "multitrait scaling analysis"[tiab] OR "multitrait scaling analyses"[tiab] OR "item discriminant"[tiab]OR "interscale correlation"[tiab] OR "interscale correlations"[tiab] OR ((error[tiab] OR errors[tiab]) AND (measure*[tiab] OR correlat*[tiab] OR evaluat*[tiab] OR accuracy[tiab] OR accurate[tiab] OR precision[tiab] OR mean[tiab])) OR "individual variability"[tiab] OR "interval variability"[tiab] OR "rate variability"[tiab] OR "variability analysis"[tiab] OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR (limit[tiab] AND detection[tiab]) OR "minimal detectable concentration"[tiab] OR interpretab*[tiab] OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR "meaningful change"[tiab] OR "minimal important change"[tiab] OR "minimal important difference"[tiab] OR "minimally important change"[tiab] OR "minimally important difference"[tiab] OR "minimal detectable change"[tiab] OR "minimal detectable difference"[tiab] OR "minimally detectable change"[tiab] OR "minimally detectable difference"[tiab] OR "minimal real change"[tiab] OR "minimal real difference"[tiab] OR "minimally real change"[tiab] OR "minimally real difference"[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF[tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])	2583865

PsycINFO search August 27, 2009 (read from top down)

No.	Query	Hits
#1	(KW=("palliati*" or "hospice*" or "end of life" or "limited life" or "terminal" or "dying*") or DE=("terminally ill patients" or "death and dying" or "hospice" or "palliative care" or "terminal cancer"))	22114
#2	DE=("religion" or "religiosity" or "spirituality") or (KW=meaning and KW=(life or death)) or KW=(spiritual* OR religion OR religious OR pastoral OR faith)	68702
#3	#1 AND #2	2806
#4	KW=("attitude measurement" or "group testing" or "individual testing" or "needs assessment" or "pain measurement" or "posttesting" or "preference measures" or "pretesting" or "psychological assessment" or "psychometrics" or "questionnaires" or "rating scales" or "reading measures" or "retention measures" or "statistical measurement" or "subtests" or "surveys" or "symptom checklists" or "testing" or	224318

No.	*Query*	*Hits*
	"geriatric assessment" or "test construction" or "test norms" or "test scores" or "testing methods" or "statistical variables")	
#5	*#3 AND #4*	*133*
#6	*DE=("religion" or "religiosity" or "spirituality") or KW=(spiritual* or religion or religious) or KW=(pastoral or faith)Limited to: Age is Aged (65 yrs & older) or Very Old (85 yrs & older)*	*3330*
#7	*#4 AND #6*	*374*
#8	*KW=meaning and KW=(life or death)Limited to: Age is Aged (65 yrs & older) or Very Old (85 yrs & older)*	*1065*
#9	*#4 AND #8*	*81*
#10	*#5 OR #7 OR #9*	*439*

CINAHL search August 27, 2009 (read from bottom up)

No.	*Query*	*Hits*
S16	*(S14 AND S15)*	*1296*
S15	*TX Instrument OR measurement OR test OR valid* OR reliab* OR responsive* OR "internal consistency" OR outcome OR reproducibility OR repeatability*	*313240*
S14	*(S9 AND S13)*	*4615*
S13	*(S10 OR S11 OR S12)*	*15139*
S12	*AB meaning and AB (life or death)*	*2400*
S11	*TI meaning and TI (life or death)*	*223*
S10	*(MH "Spirituality") or AB (spiritual* or religion or religious or pastoral or faith) or TI (spiritual* or religion or religious or pastoral or faith)*	*13198*
S9	*(S1 OR S2 OR S3 OR S4 OR S5 OR S6)*	*255032*
S6	*(MH "Attitude to Death+")*	*4719*
S5	*(MH "Aged+")*	*211882*
S4	*(MH "Terminal Care+")*	*23638*
S3	*(S2 or S1)*	*250886*
S2	*TI (palliati* or terminal or "end of life" or "limited life" or hospice* or dying*) or AB (palliati* or terminal or "end of life" or "limited life" or hospice* or dying*)*	*24223*
S1	*(MH "Palliative Care") or (MH "Hospice Care") or (MH "Terminal Care") or (MH "Chronic Disease") or (MH "Aged") or (MH "Aged, 80 and Over") or (MH "Attitude to Death")*	*242786*