

## Original Article

**Cite this article:** Spatuzzi R, Giuliotti MV, Ricciuti M, Merico F, Fabbietti P, Raucci L, Bilancia D, Cormio C, Vespa A (2019). Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients. *Palliative and Supportive Care* **17**, 294–299. <https://doi.org/10.1017/S1478951518000160>

Received: 17 February 2018

Revised: 12 March 2018

Accepted: 15 March 2018

**Key words:**

Spiritual well-being; burden; quality of life; caregiver; cancer

**Author for correspondence:**

Roberta Spatuzzi, Palliative Care Unit, “San Carlo” Hospital, Via Potito Petrone, 85100, Potenza, Italy. E-mail: [roberta.spatuzzi@yahoo.com](mailto:roberta.spatuzzi@yahoo.com)

# Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients

Roberta Spatuzzi, <sup>1</sup>PSY.D., Maria Velia Giuliotti, <sup>2</sup>PSY.D., Marcello Ricciuti, <sup>3</sup>M.D., Fabiana Merico, <sup>4</sup>PSY.D., Paolo Fabbietti, <sup>5</sup>M.SC., Letizia Raucci, <sup>6</sup>PSY.D., Domenico Bilancia, <sup>7</sup>M.D., Claudia Cormio, <sup>8</sup>PSY.D. and Anna Vespa, <sup>9</sup>PH.D.

<sup>1</sup>Palliative Care Unit, “San Carlo” Hospital, Potenza, Italy; <sup>2</sup>Department of Neurology, INRCA-IRCCS National Institute of Health and Science on Aging, Ancona, Italy; <sup>3</sup>Palliative Care Unit, “San Carlo” Hospital, Potenza, Italy; <sup>4</sup>Palliative Care Center Hospice “Casa di Betania,” Tricase (Lecce), Italy; <sup>5</sup>Biostatistical Center, INRCA-IRCCS National Institute of Health and Science on Aging, Ancona, Italy; <sup>6</sup>Hematology, “San Carlo” Hospital, Potenza, Italy; <sup>7</sup>Medical Oncology, “San Carlo” Hospital, Potenza, Italy; <sup>8</sup>Experimental Unit of Psycho-oncology, National Research Centre “Giovanni Paolo II,” Bari, Italy and <sup>9</sup>Department of Neurology, INRCA-IRCCS National Institute of Health and Science on Aging, Ancona, Italy

**Abstract**

**Objective.** The spiritual dimension is important in the process of coping with stress and may be of special relevance for those caring for cancer patients in the various phases of caregivership, although current attention is most prevalent at the end of life. This study explores the associations among spiritual well-being (SWB), caregiver burden, and quality of life (QoL) in family caregivers of patients with cancer during the course of the disease.

**Method.** This is a cross-sectional study. All participants ( $n = 199$ ) underwent the following self-report questionnaires: the SWB-Index, the Medical Outcomes Study Short Form, and the Caregiver Burden Inventory (CBI). SWB scores were dichotomized at a cutoff corresponding to the 75th percentile. Statistical analyses were made using the Student *t* or by chi-square test to compare high and low SWB groups.

**Result.** The high SWB group reported significantly better Medical Outcomes Study Short Form scores in bodily pain ( $p = 0.035$ ), vitality ( $p < 0.001$ ), social activities ( $p = 0.001$ ), mental health ( $p < 0.001$ ), and in standardized mental component subscales ( $p < 0.001$ ) than the low SWB group. No significant differences were detected between the two SWB groups in physical activity, physical role, general health, emotional status, and standardized physical component scale. The high SWB group also had better CBI scores in the physical ( $p = 0.049$ ) and developmental burden ( $p = 0.053$ ) subscales. There were no significant differences in the other CBI scores (overall and sections).

**Significance of results.** This study points out that high SWB caregivers have a more positive QoL and burden. Knowledge of these associations calls for more attention on the part of healthcare professionals toward spiritual resources among family cancer caregivers from the moment of diagnosis and across the entire cancer trajectory.

**Introduction**

In many cultural groups, spiritual well-being (SWB) is considered a positive asset for interpreting caregiving and for coping with it (El Nawawi et al., 2012; Gardner et al., 2017). Several studies (Newberry et al., 2013; Sankhe et al., 2016; Tan et al., 2015) suggest that people who are more spiritual feel more positively about their role as caregivers, get along better with those to whom they provide care, and express less caregiver distress (Skalla et al., 2013). The spiritual dimension is recognized as one of the core domains in the assessment of quality of life (QoL) in oncology (Whitford et al., 2008) and is mostly used as a coping strategy to deal with the caregiver burden (Delgado-Guay et al., 2013). Providing care to a family member with cancer has been described as a full-time job (Rabow et al., 2004) and places significant demands on the caregivers' personal time, social roles, physical and psychological states, and financial resources (Given et al., 2001).

The multidimensional burden that results from providing care to a patient with cancer is well documented; as a result, a growing number of psychosocial interventions have been developed specifically to address this burden (i.e., Meaning-Centered Psychotherapy; Applebaum & Breitbart, 2013). As reported by Given et al. (2001), it is linked to caregiver negotiations of the caregiving role because caregivers may be unfamiliar with the care they must provide and may not be aware of or able to use available resources. According to Lazarus and Folkman's original model of stress and coping (1984), if perceived demands exceed perceived resources, decreased

QoL may be one of the consequences of poor coping (Kim & Given, 2008; Lazarus, 1993). In the experience of being a caregiver for a person with cancer, finding meaning in suffering has the potential to act as a buffer against the burden (Applebaum et al., 2014).

For all these reasons, it is very important to use a biopsychosociospiritual approach to better understand all potential sources of distress in the caregiver experience. The risk is that, by failing to assess SWB, the “true” caregiver burden of cancer is largely miscalculated (Whitford et al., 2008).

SWB is not the same as spirituality. Spirituality has been conceptualized as a broader search for meaning in life, involving a universal power as guide (Underwood et al., 2006). SWB, on the other hand, is conceptualized as an expression of spirituality, or measurement of the state of one’s spirituality or spiritual health. SWB is a multidimensional concept that incorporates both religious and spiritual domains (Cotton et al., 1999) and is defined as “the ability to maintain hope and derive meaning from the cancer experience” (Ferrell et al., 1996; Prince et al., 2015). In fact SWB also differs from religiosity, defined as a formalized belief system experienced through ritual behaviors and shared religious beliefs, usually practiced in a community together with other individuals (Prince et al., 2015). SWB has many dimensions including the vertical dimension, or one’s sense of well-being in relationship to God, and the horizontal dimension that represents one’s perception of life’s purpose and satisfaction excluding any specific religious reference (Clay et al., 2010).

SWB is considered as a source of meaning in interpersonal, transpersonal, and intrapersonal processes and experiences (Adams et al., 2014). It is reasonable to consider SWB as a way of coping with stressful events such as the moment of diagnosis and across the entire cancer trajectory for a family caregiver (de Araújo Lamino et al., 2014; Puchalski, 2003).

On the basis of these considerations, we regard SWB as a universal condition that can be experienced by individuals regardless of their belonging to a particular religion and may influence family caregiver burden and QoL during the course of the disease (Colgrove et al., 2007) within a meaning systems perspective (Park, 2007). For the time being, only a few studies have examined the role of SWB in the context of providing cancer care (Adams et al., 2014; Colgrove et al., 2007; Newberry et al., 2013; Tan et al., 2015) and most of them were carried out mainly in palliative care settings (Delgado-Guay et al., 2013; Edwards et al., 2010; Sun et al., 2016). Considering this, the purpose of the present study was to explore the cross-sectional associations between SWB, burden, and QoL in primary family caregivers of patients with cancer during the course of the disease.

## Method

### Participants and procedures

The study was approved by the ethical committee of the Institutes involved. Subjects were sampled at the Oncology Clinics of two Italian general hospitals: “San Carlo” Hospital in Potenza and “Cardinale G. Panico” Hospital in Tricase (Lecce) between August 2013 and May 2014. Eligibility of primary family caregivers was based on the following criteria: having a relative with cancer; being at least 18 years of age; having no health problems; diagnosis of cancer and/or neurological or cognitive impairments; being identified as the main caregiver, either by the patient or self-

identified; being proficient in the Italian language; and providing written, informed consent.

In the clinic, 235 caregivers meeting all inclusion criteria were approached by the physician and asked to participate in the study. Of that number, 227 decided to participate and signed a consent form regarding the study protocol after detailed explanation by the physicians. The caregivers were free to complete the questionnaire either in the hospital or at home. Participants who chose to complete forms at home were given a self-addressed, stamped envelope in which to return the forms. A total of 28 caregivers did not answer all the questions in the questionnaires; it was therefore decided not to consider them for the analysis. As such, 199 primary family caregivers of patients with cancer completed the study protocol.

### Measures

All participants were asked to complete the following questionnaires:

- A. A demographic form, including data on sex and age of the patients and caregivers, educational level and employment status of caregiver, assistance timing, caregiver’s relationship to the patient, diagnosis timing, patient’s type of cancer and Eastern Cooperative Oncology Group Performance Status (Oken et al., 1982).
- B. The Medical Outcomes Study Short Form (SF-36; Brazier et al., 1992) is a multidimensional self-administered rating scale designed to assess perceived health and functioning. The SF-36 contains 36 questions and 8 subscales: (1) physical functioning; (2) role limitations from physical health problems; (3) bodily pain; (4) general health; (5) vitality (energy/fatigue); (6) social functioning; (7) role limitations because of emotional issues; and (8) mental health (psychological distress and psychological well-being). The items use Likert-type scales, some with 5 or 6 points and others with 2 or 3 points. These ratings are summed to yield raw scale scores for each health concept and are converted to a 0–100 scale, with 100 indicating the best possible score. The SF-36 also yields two summary measures—Physical Component Summary and Mental Component Summary—derived using factor analysis and designed to provide more global indexes of functioning. Scores on the summary scales are expressed as T-scores (mean = 50; SD = 10; Ware et al., 1994). SF-36 has been adapted and translated into various languages (Bullinger et al., 1998; Wagner et al., 1998) and its validity and reliability established in several countries (Gandek et al., 1998). An Italian version of the SF-36 was used for this study (Apolone et al., 1998).
- C. The Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) is a multidimensional scale proposed to evaluate the impact of burden on different aspects of a caregiver’s life, reflecting various areas of the caregiver’s well-being and functioning that may be differently affected: time-dependence burden, which gives a measure of flexibility with time and caregiver’s time restriction; developmental burden, which evaluates the impact of failing to catch opportunities and pursue goals; physical burden, a measure of the physical consequences of caregiving; social burden, which assesses the impact on interpersonal and social relationships within the family and working environment; and emotional burden, which evaluates feelings of shame and

embarrassment regarding the patient. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive), giving a total that ranges from 0 to 20 for each dimension. The total score ranges from 0 to 96, with higher scores showing higher caregiver burden. This scale has all the requirements including reliability and validity for use in clinical trials (Caserta et al., 1996; Novak & Guest, 1992). The questionnaire was translated and validated in Italian by Marvardi et al. (2005).

D. The Spiritual Well Being Index (Daaleman & Frey, 2004) contains 12 items that describe spiritual well-being. Each item is answered on a 5-point scale ranging from 1 (strongly agree) to 5 (strongly disagree). Higher scores indicate higher SWB. This test has the appropriate reliability (Cronbach's alpha = 0.804) and validity to register the complex relationship among religion, SWB, and health (Vespa et al., 2011).

### Statistical analysis

Sociodemographic characteristics of both patients and caregivers were listed using descriptive statistics. The 75th percentile was adopted as a cut point to identify caregivers with high and low SWB. We decided on this dichotomization as the value that better discriminated our sample according to the aim of the study because it has already been carried out in a previous study (Vespa et al., 2011). The reliability of the SWB index was assessed by Cronbach's coefficient alpha. Statistical comparisons were performed by Student t or by chi-square test to compare high and low SWB groups. Data were analyzed using the SPSS statistical software package (SPSS, Chicago, IL), version 19.0, for Windows. All tests were considered significant at  $p \leq .05$ .

### Results

From the reliability analysis of the SWB index using Cronbach's alpha coefficient, significant congruence and reliability emerged (Cronbach's alpha = 0.804).

The sociodemographic characteristics of both groups (low SWB group vs. high SWB group) are shown in Table 1. Low and high SWB groups of participating caregivers did not differ with regard to sex and age of caregiver, educational level, employment status, assistance timing, type, sex or age of patient, diagnosis timing, type of cancer, and patient's Eastern Cooperative Oncology Group Performance Status.

### Spiritual well-being and QoL

Compared with low SWB caregivers, the high SWB group reported significantly better SF-36 scores in bodily pain ( $p = 0.0359$ ), vitality ( $p < 0.001$ ), social activities ( $p = 0.001$ ), mental health subscales ( $p < 0.001$ ), and in standardized mental component scale ( $p < 0.001$ ). No significant differences were detected between the two groups in physical activity, physical role, general health, emotional status, and standardized physical component scale (Table 2).

### Spiritual well-being and caregiver burden

Compared with caregivers with high SWB, the low SWB group reported significantly higher scores in two CBI subscales: physical ( $p = 0.049$ ) and developmental burden ( $p = 0.053$ ). No further

**Table 1.** Sociodemographic characteristics of the patients and caregivers by SWB groups (low and high)

Variable	Low SWB (n = 52)	High SWB (n = 147)	p
Patient's sex			0.242
Male	22 (42.3%)	77 (52.4%)	
Female	30 (57.7%)	70 (47.6%)	
Patient's age			0.188
	64.02 (13.96)	67.07 (15.10)	
Caregiver's sex			0.536
Male	15 (28.8%)	36 (24.5%)	
Female	37 (71.2%)	111 (75.5%)	
Caregiver's age			0.146
	47.48 (12.74)	50.52 (13.14)	
Caregiver's education level			0.489
Illiterate	0 (0.0%)	2 (1.4%)	
Elementary	4 (7.7%)	6 (4.1%)	
Middle school	16 (30.8%)	53 (36.0%)	
High school	22 (42.3%)	67 (45.7%)	
University	10 (19.2%)	19 (12.8%)	
Caregiver's employment status			0.883
Employed	22 (42.3%)	67 (45.6%)	
Unemployed	12 (23.1%)	27 (18.4%)	
Housewife	11 (21.2%)	30 (20.4%)	
Retired	7 (13.4%)	23 (15.6%)	
Assistance timing			0.351
24 hours per day	24 (46.2%)	55 (37.4%)	
Night	2 (3.8%)	3 (2.0%)	
3 hours per day	5 (9.6%)	8 (5.4%)	
4–6 hours per day	9 (17.3%)	29 (19.7%)	
7–12 hours per day	12 (23.1%)	52 (35.5%)	
Patient type			0.108
Wife	11 (21.2%)	16 (10.9%)	
Husband	7 (13.5%)	28 (19.5%)	
Father	14 (26.9%)	34 (23.1%)	
Mother	19 (36.5%)	39 (26.2%)	
Son	0 (0.0%)	6 (4.0%)	
Other	1 (1.9%)	24 (16.3%)	
Type of cancer			0.379
Breast	16 (30.9%)	47 (31.9%)	
Lung	12 (23.0%)	42 (28.5%)	
Colon	12 (23.0%)	34 (23.2%)	
Leukemia	8 (15.3%)	13 (8.9%)	
Other	4 (7.8%)	11 (7.5%)	
Diagnosis Timing (days)			0.819
M (SD)	599.72 (961.19)	634.39 (798.28)	
Minimum-maximum	30–5,475	30–4,754	

(Continued)

**Table 1.** (Continued.)

Variable	Low SWB (n = 52)	High SWB (n = 147)	p
Patient's Eastern Cooperative Oncology Group Performance Status			0.489
0	0 (0.0%)	2 (1.3%)	
1	4 (7.7%)	6 (4.1%)	
2	16 (30.8%)	53 (36.1%)	
3	22 (42.3%)	67 (45.6%)	
4	10 (19.2%)	19 (12.9%)	

SWB, spiritual well-being.

differences were found between the two SWB groups in the other CBI scores (overall and sections) (Table 2).

## Discussion

In this study we have attempted to measure SWB from the perspective of the cancer caregiver. Comparing the psychometric measures between the low and high SWB group, no statistically significant sociodemographic differences were found. Conversely, we observed many significant differences between these two groups in caregiver burden and QoL.

**Table 2.** Psychometrics measures statistics for SWB groups

Measures	Low SWB (n = 52)	High SWB (n = 147)	p
	M (SD)	M (SD)	
SF-36			
Physical activity	75.86 (29.58)	76.05 (29.07)	0.968
Physical role	37.01 (40.06)	44.04 (42.73)	0.288
Bodily pain	51.34 (27.41)	60.87 (28.11)	0.035
Health in general	50.67 (23.05)	56.68 (22.05)	0.106
Vitality	35.28 (16.22)	47.61 (20.85)	<0.001
Social activities	39.66 (18.64)	50.93 (24.08)	0.001
Emotional status	23.71 (37.53)	35.48 (40.22)	0.060
Mental health	34.76 (16.22)	50.53 (20.96)	<0.001
Standardized physical component	45.93 (12.08)	46.32 (11.43)	0.841
Standardized mental component	27.08 (8.81)	34.91 (11.38)	<0.001
CBI			
CBI time dependence	11.25 (5.79)	12.04 (5.89)	0.402
CBI social	7.96 (4.99)	7.18 (5.45)	0.349
CBI physical	6.73 (4.01)	5.44 (3.91)	0.049
CBI developmental	4.01 (3.92)	2.80 (3.61)	0.053
CBI emotional	1.69 (3.03)	1.21 (2.39)	0.304
CBI overall score	31.65 (14.75)	28.68 (15.27)	0.220

CBI, Caregiver Burden Inventory; SF-36, Medical Outcomes Study Short Form; SWB, spiritual well-being.

In particular, the high SWB group showed better SF-36 scores for bodily pain and mental health subscales and for the standardized mental component scale, although no significant differences were detected in physical activity, physical role, general health, emotional status and standardized physical component scale. In line with Delgado-Guay et al. (2013), these results suggest that SWB acts as a protective factor against psychological and physical distress.

For many years, SWB has been regarded as a component of patient care in fields closely related to pain medicine such as palliative and supportive care. Despite this, it has received relatively little attention within the field of pain medicine itself. Interestingly, in this study we observe a relationship between SWB and bodily pain. Our observations are consistent with the results of Siddall et al. (2015), who found increasing evidence to support the inclusion of spiritual factors as an important component in the assessment and treatment of pain. Further studies will be needed to explore the changing conceptual frameworks that have been applied to pain medicine, the emergence of the biopsychospiritual approach (Puchalski, 2012) and its meaning, as well as finding evidence for the benefits of incorporating this approach for the management of pain.

The high SWB group scored better also for vitality subscale. This result shows the importance of implementing vitality, defined as a "positive feeling of having energy available to the self" (Nix et al., 1999), as a significant dimension of spiritual health in family caregivers of patients with cancer (Griggs et al., 2007; Ryan & Frederick, 1997).

Findings of our study also demonstrated that SWB is an important personal resource that can be drawn upon to facilitate improvements in social well-being. Many spiritual traditions encourage participation in a community. Spiritual fellowship, such as attending church or a meditation group, can be sources of social support that may provide a sense of belonging, security and community (Powell et al., 2003).

High SWB of primary family caregivers also has positive outcomes on CBI developmental and physical burden subscales although in the other CBI subscales (time dependence, social, and emotional) and CBI overall score no difference emerged. On the basis of our results, caregivers with low SWB perceive a greater sense of isolation from the expectations and opportunities of their peers and describe a greater feeling of chronic fatigue and somatic health issues. In accordance with Newberry et al. (2013), our findings suggest that SWB is an important factor that can influence caregiver burden and physical health. Maintaining faith and finding meaning in cancer caregiving can buffer the adverse effect of caregiving stress on mental health. Caregivers with high SWB should also be encouraged to pay more attention to their physical health while providing cancer care (Colgrove et al., 2007).

These results introduce a meaning-centered model (Park, 2007) of well-being and QoL for family cancer caregivers. Highly spiritual cancer caregivers may perceive caregiving as a part of their spiritual duties, yielding positive appraisals of their caregiving experience even while neglecting self-care. As reported by Colgrove et al. (2007), family caregivers may experience physical detriment from providing intense cancer care or from additional stress related to acting in accordance with spiritual norms and still perceive their caregiving role positively because they are fulfilling a spiritual calling (body sanctification; Jacobson et al., 2013; Park, 2007). In line with Applebaum et al. (2014), we believe that these caregivers may already be making meaning of this role and/or finding benefit in caregiving, despite their

burden. By promoting interconnectedness with self, others, and God, and providing guidance in the search for life's meaning and purpose, high SWB caregivers may transcend their suffering and experience a greater sense of QoL and decreased burden throughout the disease process of cancer patients (Tan et al., 2015). This dynamic process may explain how physical and mental health are better in highly spiritual cancer caregivers. Our study has several methodological limitations such as the cross-sectional design, dichotomization, as well as its focus on QoL and burden, and a lack of comparison between groups for different tumors. This type of comparison was not been possible because of the limited number of cases in the subdivision for each type of cancer given the small sample size. Measures of caregiving demands and caregivers' attachment patterns, coping styles, personality traits, and perceived social support were not included; thus, many confounders were not considered. Furthermore, all of the analyses were univariate, meaning that none of the analyses control for possible confounders. This may overstate the relationship between SWB and positive outcomes. Despite these limitations, our findings have theoretical implications for better understanding the practical implications for developing integrative programs to improve QoL of family members in the various phases of caregivership (Kim et al., 2011). Currently, attention to spiritual needs is most prevalent at the end of life. Cancer treatment, whether its intent be curative or palliative, can be a demanding period for the family caregiver both physically and mentally. Some existential therapeutic models such as, for example Meaning-Centered Psychotherapy (Breitbart et al., 2012, 2015), demonstrating efficacy in improving spiritual well-being and a sense of meaning, might be desirable to address and resolve the issue. Assisting caregivers to access sources of meaning in the caregiving experience should lead also to improvements in their QoL (Applebaum et al., 2014).

This study shows that psychosocial care and spiritual support should be made available to family caregivers from the moment of cancer diagnosis, already in active treatment settings, and not only in palliative care (Puchalski et al., 2014). It is important to acknowledge the family's specific beliefs and emotions connected with grief, and that healthcare professionals need to be prepared about the spiritual and existential concerns they may come to face throughout the caring process. Only a biopsychosociospiritual approach can help those suffering from cancer and their caregivers to reevaluate the meaning of their life, which has been, often abruptly, undermined by the disease (Puchalski, 2012). More research is needed to help develop new ways of supporting the specific needs of family caregivers during times of great vulnerability.

## Conclusion

This study highlights the role of SWB upon the burden and QoL of family caregivers pointing out that it could be useful in preventing pathological influences of the caregiver burden and enhance psychological and physical well-being through spiritual counseling. The presence of a spiritual dimension may be a marker for a better adaptation to caregiving.

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