

Spirituality in patients with advanced illness: The role of symptom control, resilience and social network

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Abstract

In this study, we analyzed the relationships among clinical, emotional, social, and spiritual dimensions of patients with advanced illness. It was a cross-sectional study, with a sample of 108 patients in an advanced illness situation attended by palliative care teams. Statistically significant correlations were found between some dimensions of spirituality and poor symptomatic control, resiliency, and social support. In the structural model, three variables predicted spirituality: having physical symptoms as the main source of discomfort, resiliency, and social support. This work highlights the relevance of the relationships among spirituality and other aspects of the patient at the end of life.

Keywords

clinical symptoms, palliative care, resilience, social support, spirituality

Introduction

The main aim of palliative care is to reduce suffering, the latter being a complex, personal, and multidimensional experience. Suffering is defined as “the emotional state produced when the integrity of the person is threatened or broken, and that persists until the threat disappears or the integrity is restored or transcended” (Casell, 1982). Health has been defined as a multidimensional construct as follows: “Health is a state of well-being with satisfaction of physical, cultural, psychosocial, economic and spiritual needs, not simply the absence of illness” (Marks et al., 2015). Taking into consideration this definition, the possible causes of threat to the personal integrity of patients

with needs of palliative attention are multiple and might affect different aspects of health.

In the context of palliative care, special attention has been paid to the care of physical aspects that generate discomfort and suffering (Doyle

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et al., 1993). There is growing evidence on the importance of psychological and social aspects when attending the patients' distress and their families (Bennett and Shepherd, 2012; World Health Organization (WHO), 2002). In this sense, the importance of resilience when attending to the patients' emotional needs with palliative care has been recently highlighted. As Radbruch et al. (2009, 2010) have pointed out, palliative care supports a vision of health in which not only the patients' difficulties but also their resources and competences need to be emphasized. In this context, resilience, measured as a coping process, has been related to physical and psychological positive results in palliative context (Krikorian and Limonero, 2012). It should be borne in mind that different approaches to the construct of resilience can be addressed in the scientific literature under different expressions, for example, as "learned resourcefulness" in Lai et al. (2014).

In the past few years, aspects of spirituality have emerged as an important need, and an understanding that spirituality is a more holistic and inclusive concept than religion (Bekke-Hansen et al., 2014; Vachon et al., 2009; Visser et al., 2009). In this direction, the number of scientific papers that deepen our understanding of the conceptual aspects of spirituality, the difficulties of its assessment, and the training needs of palliative care staff has grown considerably.

Nowadays, some consensus about the definition of "spirituality" seems to be reached in the scientific literature (Puchalski et al., 2009). The European Association for Palliative Care (EAPC) defines it as

the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. (Nolan et al., 2011)

It could be said that people can keep their spiritual integrity as long as they maintain their network of relationships, including the relationship with themselves (intrapersonal), with

others (interpersonal), and with the transcendence or divine (transpersonal). On the other hand, progress has been made in the study of the relationships among spiritual and psychological well-being and physical symptoms (Barreto et al., 2015; Monroe and Oliviere, 2007). Likewise, there is evidence on the relationships among resilience, perceived symptoms, and physical functionality (Krikorian and Limonero, 2012; Terrill et al., 2014).

We find in the literature data pointing out the way in which spiritual well-being can be related to variables like pain management (Hui et al., 2011), functional status, type of pathology (Haghi et al., 2012), and management of physical symptoms (Kandasamy et al., 2011). However, the studies in this field are limited (Delgado-Guay et al., 2011) and approach these variables separately, lacking evidence about the way and extent to which they interact. Studies focused on these aspects would be of great help in the clinical management of the patients' difficulties at the end of life.

In this work we aimed to analyze, in a comprehensive way, the existing relationships among different factors of the clinical, the emotional, the spiritual, and the social fields that configure the patient's situation at the end of life.

Materials and method

Design, procedure and sample

The analyses were focused on a sample of 108 patients that fulfilled the inclusion criteria: to be 18 years or older, to have an advanced terminal disease according to the WHO, to have comprehension ability to understand subjective measures, to be aware of diagnosis and occasionally express the possibility of dying, and to have provided informed consent (see Supplementary file 1). It was a cross-sectional multi-centre study carried out in 15 nationwide palliative care teams in Spain (Supplementary file 2, which contains the names of the 15 participating hospitals). Participants came from palliative care units (47.5%), home care palliative services

(36.4%), palliative units in acute care hospitals (16.5%), and nursing homes (10%).

Instruments

In addition to questions about sociodemographic data, information on the following aspects was collected.

Spirituality. This was assessed with a questionnaire of the Task Force on Spiritual Care (GES) from the Spanish Society of Palliative Care (SECPAL) (Benito et al., 2014) that comprises six open questions designed to facilitate patient's trusting revelations on their biography and inner world, followed by eight items assessing spirituality as a general factor and three spiritual dimensions: intrapersonal, interpersonal, and transpersonal. The patient answers the extent to which he or she feels identified with each item, using a scale from 0 ("not at all") to 4 ("a lot"). Mean scores were calculated for each dimension. Cronbach's alpha was .71.

Resilience. We used the Brief Resilient Coping Scale (Tomás et al., 2012), translated and validated in Spain. It is a four-item scale, where each item is rated on a 5-point Likert scale, from 1 ("totally agree") to 5 ("totally disagree"), with higher scores reflecting greater resilience. Mean scores were computed. Internal consistency was .79.

Bad symptomatic control. This variable was assessed using the scores obtained in the Spanish adaptation of the Edmonton Symptom Assessment Scale (ESAS) (Centeno et al., 2004; Mehle et al., 2014), which contains 10 numeric scales that assess the intensity of the symptoms taking into account the patient's conditions in the last 48 hours. Cronbach's alpha was .81. This variable summarizes the scores of each symptom in two groups: "controlled" or "not controlled" (scores equal or higher than 5 would fit into "not controlled"). Adding the number of "not controlled" symptoms, this variable offers scores from 0 to 10 (meaning the number of uncontrolled symptoms).

Social support network. This variable summarizes different aspects of the patient's way of living together using a coexistence model. Patients might live with their partners, children, and relatives, or in an institution. In the same way, there might be one or several caregivers, who might be the patients' partner, a close relative, a volunteer, or someone hired to that effect. Conditions of social support, like living together, care giving, and keeping company, were rated as "1." Likewise, loneliness conditions were rated as "0." Adding these ratings, we approximate to a measure of the patients' social support network, with higher scores meaning a bigger social support network.

Concern and discomfort related to symptomatology. These variables were assessed with two questions: "What worries you the most?" and "What bothers you the most?" The answers to these questions were categorized in vivo by a group of three independent clinical and methodological experts in palliative care. Once all the categories were identified and labeled for the entire universe of responses, a fourth researcher assigned responses to their corresponding category. This classification obtained the agreement by consensus of all the researchers and was introduced into the database with the quantitative data. Regarding the question about worries, those answers related to physical symptomatology were categorized as "Concern About Pain" (CAP). Likewise, from the answers about what caused them more discomfort, those related with physical symptomatology were categorized as "Main Discomfort Symptoms" (MDSs). The prevalence of these two categories was studied.

Statistical analyses

Basic statistical analyses of central tendency and variability were computed with SPSS 20, as well as the frequency of prevalence of the categories of interest. For the bivariate analyses, Pearson's correlations were obtained for the quantitative variables, and contingency tables with χ^2 were calculated for the qualitative ones.

To carry out more complex multivariate analyses, Structural Equation Modeling Software (EQS 6.1) was used. Structural equation models were calculated in order to explain the relationship between emotional, social and spiritual well-being, and symptomatology. To evaluate the fit of the model to the data, several indices were calculated: (a) chi square (χ^2) statistic, with values that are not statistically significant indicating an adequate fit (Kline, 1998); (b) comparative fit index (CFI), that is reasonable with values higher than .90 (>.95 is considered ideal) (Bentler, 1990); (c) goodness-of-fit index (GFI), higher than .90 indicating a good adjustment (Tanaka, 1993); (d) standardized root mean square residual (SRMR), lower than .08 meeting goodness-of-fit criteria; and (e) root mean square error of approximation (RMSEA), equal or lower than .05, indicating adequate fit.

Results

Descriptive results

From the 108 participants, 51.9 percent were women. The age range was 41 to 94 years, with a mean age of 68.09 years (standard deviation (SD)=12.71 years). Clinical and sociodemographic characteristics, such as type of health care service, marital status, main caregiver, educational level, and diagnosis, are shown in Table 1.

The bad symptomatic control (BSC) mean value was 3.57 (SD =2.58). Thus, having between 3 and 4 bad controlled symptoms is representative of these patients. The distribution of the BSC showed that 17 patients (15.7%) had their symptomatology completely controlled (BSC=0) and 3 patients (2.8%) had all of their symptoms badly controlled (BSC=10) (see Supplementary file 3).

When patients were asked about their worries and bothers, family appeared as the most prevalent worry (51% of the patients), followed by pain (33.7%). As regards the main cause of discomfort, 34.6 percent of the patients pointed symptomatic control (see Supplementary file 4).

Regarding the descriptive statistics of quantitative variables, the dimensions of spirituality showed means of 2.99 (SD =.66) for the intrapersonal, 3.42 (SD =.74) for the interpersonal, and 2.98 (SD =1.01) for the transpersonal spirituality. Resilience showed a mean of 3.50 (SD =1.00) and social support network a mean value of .09 (SD =.28). Statistics of variability were appropriate, pointing to sample homogeneity.

Bivariate study of the relationship among situational variables, physical and spiritual well-being, and resilience

A complementary analysis was carried out using a contingency table, but no statistically significant association was found between the categories "CAP" and "Discomfort by Symptoms" ($\chi^2(1)$ =.236; p =.627). Although, an intuitive relationship between higher symptom discomfort and concern about these symptoms would have been expected (that is, the patients with more discomforting symptoms would be those with higher concerns about symptoms), the analysis showed no relationship between these two variables. Thus, these variables provide non-redundant information about two different aspects. Correlations among BSC, resilience, social support network, spirituality, and age can be observed in Table 2.

Multivariate model of relationships between the variables

The bivariate analyses of the spirituality dimensions and relevant variables of the patients' clinical and personal situation were taken as a starting point. Two models of structural equations Multiple Indicators Multiple Causes (MIMIC) were estimated in order to answer the hypotheses of relationships between all the variables considered together. At first, it was computed a theoretical model that included an effect of gender, type of diagnosis (cancer vs no cancer), CAP, symptoms as main discomfort, resilience, social support network, and BSC; on the general factor of spirituality. At the same time, this general factor of

Table 1. Patients' distribution according to clinical and sociodemographic characteristics (N= 108).

According to diagnosis	
Cancer	85% (91)
Digestive system neoplasia (digestive tract and hepatobiliopancreatic)	34.1% (31)
Pulmonary neoplasia	19.8% (18)
Bladder neoplasia and urinary tract neoplasia	8.8% (8)
Breast neoplasia and gynecological neoplasia	16.5% (15)
Other neoplasias (hematological, cutaneous, head, and neck, unknown primary)	20.8% (19)
Other than cancer	15% (16)
Heart disease	18.7% (3)
Respiratory disease	12.4% (2)
Renal disease	6.3% (1)
Neurological disease	50% (8)
AIDS	6.3% (1)
Other pathologies without neoplasia	6.3% (1)
According to the type of care setting	
Palliative Care Unit, acute care setting	18.5% (20)
Palliative Care Unit, chronic care setting	48.1% (52)
Domiciliary hospitalization (DH)	22.2% (24)
Geriatric residence	11.1% (12)
According to marital status	
Single	12.9% (13)
Married/stable partner	50.5% (51)
Divorced	13.9% (14)
Widower/widow	20.8% (21)
Other	20.8% (21)
According to the main caregiver	
Alone	12.6% (13)
Partner or close relative	42.7% (44)
Son/daughter or sibling	32.0% (33)
Other relatives	9.7% (10)
Friends	2.9% (3)
According to the educational level	
None	9.5% (10)
Primary	40.0% (42)
High school	19.0% (20)
Professional education	7.6% (8)
University	23.8% (25)

spirituality explained three spirituality dimensions: intrapersonal, interpersonal, and transpersonal. The model also included two covariances between predictors; this is, between diagnosis and symptoms as main discomfort and between resilience and BSC. These covariances were proposed based on a previous bivariate study carried out in this research. This model did not obtain a good fit of the data: $\chi^2(33)=46.58$ ($p>.05$), CFI=.791, GFI=.918, SRMR=.077, and RMSEA=.066 (confidence interval was .001-.106).

Afterwards, a second model was computed, following the suggestion of the Lagrange multiplier (LM) test. Concretely, a positive effect of the social support network on the interpersonal dimension of spirituality was specified. This model showed an acceptable general fit of the data, with $\chi^2(32)=35.03$ ($p>.05$), CFI=.951, GFI=.932, SRMR=.068, and RMSEA=.032 (confidence interval was .001-.083). There were three statistically significant predictors of the general factor of spirituality: resilience, social support network, and having as main discomfort the symptoms (see Figure 1). Specifically, the general factor of spirituality was positively predicted by resilience and negatively predicted by both having symptoms as main discomfort and a big social support network. In addition, the model also showed a statistically significant negative covariance between BSC and resilience. Thus, even though bad control of symptoms did not affect the general factor of spirituality directly, it did indirectly through its effect on resilience. There was also found a significant positive covariance between the type of diagnosis and having symptoms as main discomfort, being the latter higher in cancer as type of diagnosis. All these effects taken together explained 41.9 percent of spirituality's variance.

In regard to the dimensions of spirituality, the three of them were positively explained by spirituality. We also observed a positive effect of social support network on the interpersonal spirituality dimension. The explained variance was 23.9 percent for the intrapersonal dimension, 40.7 percent for the interpersonal, and 39.7 percent for the transpersonal.

Table 2. Pearson's correlations among the variables of study.

	1	2	3	4	5	6	7	8
1. Age	1	–	–	–	–	–	–	–
2. CAP	.105	1	–	–	–	–	–	–
3. MDS	-.101	.048	1	–	–	–	–	–
4. Resilience	.080	.153	-.001	1	–	–	–	–
5. Social support network	-.030	-.018	-.018	.048	1	–	–	–
6. BSC	.066	-.038	.114	-.263**	-.058	1	–	–
7. Intrapersonal spirituality	.013	.018	-.073	.208*	-.005	-.195*	1	–
8. Interpersonal spirituality	.084	-.017	-.125	.231*	.202*	-.223*	.476**	1
9. Transpersonal spirituality	.098	.010	-.289**	.305**	-.184	.033	.229*	.270**

CAP: concern about pain; MDSs: main discomfort symptoms; BSC: bad symptomatic control.

* $p < .05$; ** $p < .01$.

Discussion

Regarding the prevalence of BSC, data from our study support previous research. The more prevalent symptoms in our research were low sensation of well-being, insomnia, anorexia, pain, somnolence, asthenia, low mood, and nervousness. There is abundant literature on the analysis of these symptoms (Ferris et al., 2002; Sigurdardottir and Haugen, 2008; Steiger and Lind, 1980), and though there is some agreement about the more frequent symptoms, the prevalence for each of them remains unclear. This might be due to the influence of multiple factors such as the type of pathology, the stage of medical condition, the type of care service, and methodological aspects (Potter et al., 2003; Teunissen et al., 2007).

Always taking into account that individual differences play an essential role in the degree of concern that patients have about their symptoms (Solano et al., 2006), one of the aims of this study was to provide useful information on the patients' concern about their symptoms, and on the extent to which symptoms and physical discomfort bother them. Our results show that when patients are asked with open questions about the aspects that bother them the most, symptoms' control appears in the first place. However, the main cause of worry and suffering among patients is the suffering of their beloved ones, rather than their own pain. Besides, no significant association between

main cause of bother and main cause of suffering has been detected using a bivariate analysis. Thus, this interaction is more complex than it could seem. Based on clinical experience, this may be explained by the fact that patients may have a bad control of symptoms but focus their attention on other aspects of themselves and their surroundings. Similarly, a good control of physical symptoms does not assure quality of life and well-being. Therefore, besides the assessment of symptoms' presence and intensity, it is also relevant to assess with scientific guarantees the degree of suffering that these symptoms might produce. Beyond the mere identification of problems, it is necessary to analyze in depth the factors that might be affecting the patients' suffering. In this sense, our results support some of those found in the literature (Barreto et al., 1996; Laugsand et al., 2011; Lloyd-Williams et al., 2004).

Concerning the main aim of our work, results show interactions between spirituality's components and different factors, such as physical symptoms, resilience, and social support network. Delgado-Guay et al. (2011) point in the same direction: spiritual discomfort is associated to higher levels of depression, anxiety, anorexia, and somnolence. In the same way, patients with spiritual pain are prone to rate their physical and emotional symptoms as worst.

Indeed, our work's most interesting results are those derived from the multivariate analysis (MIMIC model). The structural equation model

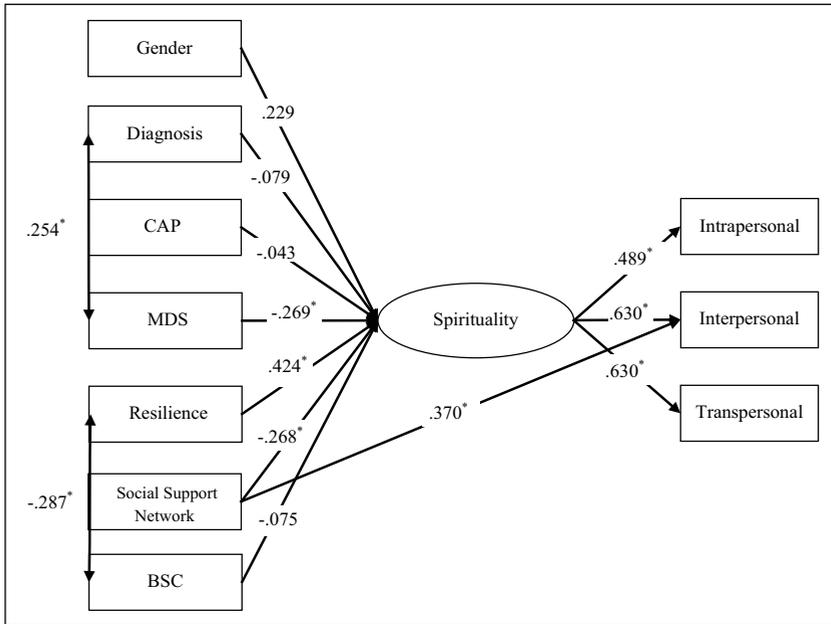


Figure 1. Final model.

CAP: concern about pain; MDSs: main discomfort symptoms; BSC: bad symptomatic control.

* $p < .05$.

presents a good fit and allows us to discover the explanatory capacity of variables that help defining the patient’s vital situation (gender, diagnosis, CAP, discomfort because of symptoms, resilience, social support network, and control of symptoms), supporting existing evidence on the relationship between spirituality and these variables (Delgado-Guay et al., 2011; Hagi et al., 2012; Hui et al., 2011; Kandasamy et al., 2011). Moreover, the general factor of spirituality explains positively its three dimensions: intrapersonal, interpersonal, and transpersonal.

In regard to results concerning resilience, these are in line with the new approach to resilience that has arisen during last years in palliative care. Within this context, resilience is referred to the ability of patients to cope with incurable illness and the derived problems, that is to say, to cope with the new point of view that gives a limited life expectancy (Radbruch et al., 2009). In this study, resilience has been the variable with the higher predictive value for spirituality, which is in line with Vanistendael’s

(2007) approach to resilience: resiliency and spirituality are closely related, sharing both an element of meaning at their basis. Thus, this relation is a central component when addressing the resources and needs of patients in palliative care.

There is a direct positive effect of the social support network on the interpersonal dimension of spirituality, so that a good support from family or social context would promote spiritual well-being on its interpersonal dimension. From this can be deduced the importance of strengthening the patient’s interpersonal relationships and the proper care of the caregiver, in order to provide well-being and high quality attention to the patient. The model also shows a significant negative relationship between the general factor of spirituality and social support network. This result needs to be clarified, considering that the relationship between social support network and each dimension of spirituality was different (positive with interpersonal, negative with transpersonal, and non-existent

with intrapersonal). A possible explanation for this could be that people with smaller social support network might develop a higher sense of transcendence or backwards: those with higher transpersonal spirituality might not keep a big social support network. A limitation from this study is that only the size of social support network was assessed, but not the quality of it. Future research should address the quality and the perception of social support, and not only its size. Therefore, current findings must be cautiously considered. As an additional limitation it can be pointed out that although a strong agreement by experts' consensus was reached on the identification and classification of the patients' main concerns, no inter-rater reliability data were gathered.

The model also shows a statistically significant negative covariance between BSC and resilience. In this way, although BSC does not affect the general factor of spirituality directly, it might do it indirectly, through its effect on resilience. To some extent, it could be interpreted that physical suffering intensifies emotional discomfort, blocking strengths, and personal resources that conform spirituality.

In essence, this work sought to highlight the importance of acknowledging patient's spirituality, that "forgotten factor" in the words of Crowther et al. (2002), as a facet that needs to be assessed and taken care of in palliative care. As clinicians, if we wish to optimize the quality of the attention that patients at the end of life receive, the relationships between spirituality and the clinical situation need to be taken into account. Therefore, the aspects that have been found strongly related to spirituality, such as symptom control, resilience, and social support network, must be considered in the design and implementation of future intervention programs. In order to improve the patient's well-being, it is necessary to attend to physical, emotional, social, and spiritual aspects.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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