Predictors of Suffering in Advanced Cancer

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Abstract

Context: Suffering is a complex experience. Identifying its predictors is useful to signal at-risk patients. **Objective:** To identify suffering predictors in patients with advanced cancer in palliative care. **Methods:** A total of 98 patients participated in the study. A semistructured interview examining suffering levels and physical, psychological, social, and spiritual aspects was used. Instruments included Pictorial Representation of Illness and Self Measure (PRISM), Edmonton Symptom Assessment System (ESAS), Detection of emotional distress (DED), and Structured Interview of Symptoms and Concern (SISC). Variance-based structural equation model was used for the data analysis. **Results:** All measures were valid and reliable. The structural model explained 64% of the variance. Suffering levels were directly determined by psychological and adjustment problems and indirectly determined by physical, psychological, and spiritual aspects and coping strategies. **Conclusion:** Our study supports the proposed theoretical model and signals the important mediating effect of psychological and spiritual variables between physical symptoms and suffering.

Introduction

Cancer represents a major health problem worldwide.[1] Particularly, advanced cancer is not only a deteriorating condition for patients and families in the whole world but also highly prevalent in developing countries, where resources are limited, and palliative care (PC) services are still under development.[2,3] Moreover, patients with advance cancer frequently face multiple and deteriorating symptoms and problems that may lead them to severe suffering.[4]

Suffering is a common human experience when facing events that threaten the intactness of the person or when experiencing significant losses.[5,6] Most people have an implicit understanding of the suffering experience; however, its definition and operationalization in the health care field is still a subject of debate.[7,8] This has become an important issue, since the World Health Organization included suffering relief as one of the main objectives of PC.[1] Therefore, detection and management of suffering in the clinical practice are central for optimal patient care.

Suffering is a complex and comprehensive experience entailing physical, psychological, social, and spiritual correlates.[8-10] Cassell, one of the pioneers of the study of suffering in health care, defines it as "a specific state of severe distress related to the imminent, perceived, or actual threat to the integrity or existential continuity of the person."[5,9,10] A more recent definition of the concept considers it "a multidimensional and dynamic experience of severe stress that occurs when there is a significant threat to the whole person and when the regulatory processes, which would normally result in adaptation, are insufficient leading to exhaustion."[8] As stated in both the definitions, suffering is subjective in nature and entails an integrative experience while directly relating to threat perception and insufficient resources to cope.

Interest in conceptualizing and examining illness-related suffering has grown in the last decades.[4-6,11-16] As a result, some conceptual frameworks to understand suffering in chronic and life-threatening diseases have been developed in order to guide assessment and treatment options.[8,17-19] Krikorian and Limonero[8] recently presented a view of suffering that integrates relevant theoretical considerations related to suffering, distress, and stress. The authors state that internal or external events that affect the person as a whole (including physical, psychological, spiritual, and sociocultural dimensions) are perceived and mediated by emotion. At the same time, regulatory and coping processes in each dimension are triggered. When coping resources are insufficient and the person's integrity is continued to be threatened and eventually damaged, exhaustion occurs leading to suffering. According to this mediation model of suffering, the symptoms

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or problems experienced by people with life-threatening conditions (eg, common physicals symptoms like pain) may cause or accompany emotional distress while having an impact on other dimensions of personal experience.

As well, instruments and strategies to facilitate suffering detection have been developed,[11,20-25] and interest in the aspects linked to the suffering experience has increased. Factors associated with suffering have been found to be multiple and to change from person to person depending on individual-, contextual-, and illness-related conditions.[4,7,26,27] Related factors may include issues in the physical, psychological, sociocultural, and spiritual/existential dimension. A synergy among them is usually seen,[4] since the persistence of problems in one of the mentioned dimensions can produce or aggravate problems in other dimensions, leading to an overall increase in suffering for patients and their families.[4,8] This makes early detection and alleviation of suffering particularly challenging.

Therefore, efforts oriented at identifying predictors of suffering in different contexts may be useful, as they may signal risk factors and the need for a more thorough assessment in particular cases and its corresponding clinical intervention. It may also provide support to the mediation model presented, which will allow for a better understanding and management of suffering in patient care. With this objective in mind, the current study aims at identifying predictors of suffering in patients with advanced cancer in PC, following the integrated view proposed by Krikorian and Limonero.[8]

Methods

Participants

A total of 209 patients with cancer consecutively attending a PC service within a regional reference oncology institution in Colombia were invited to participate in the study between April and September 2011. Eligibility criteria were being older than 18 years, being diagnosed with advanced cancer with a life expectancy of less than 6 months (according to the criteria of the attending specialist in PC), and no longer receiving active oncologic treatment. Inclusion criteria included voluntary acceptance to participate as well as the family and clinician's agreement to enroll in the study given the patient's physical and mental state, having an adequate cognitive functioning (as examined during their regular PC consultation), and being in a condition well enough to participate in a 45-minute interview. The study was approved by the institution's ethics committee. Of the eligible patients, 46.88% (n = 98) fulfilled the inclusion criteria, accepted to participate, and gave written informed consent. Reasons for no participation are detailed in Table 1, while sociodemographic and clinical data of participants are presented in Table 2.

Measures

Data regarding sociodemographic and clinical aspects were recovered from clinical charts. A semistructured interview was designed to examine suffering levels, physical psychological,

Table 1. Reasons for No Participation.

Reasons	n (%)
Feeling too ill to participate	51 (30.62)
Delirium	21 (10.4)
Not interested in participating	10 (4.7)
Verbal communication problems	10 (4.7)
Others related to mobility and familial issues	5 (2.7)
Total	106 (100)

Table 2. Sociodemographic and Illness-Related Data.

Variable	Category	n (%)
Marital status	Single	14 (14.3)
	Lives with partner	53 (54.1)
	Divorced/separated	17 (17.3)
	Widowed	14 (14.3)
Religion	Catholic	90 (91.8)
	Other	8 (8.1)
Years of education	<6	53 (53)
	Between 6 and 12	21 (21.4)
	>12	24 (24.5)
Place of residence	Urban	85 (86.7)
	Rural	13 (13.3)
Cancer type	Lung	18 (18.4)
	Breast	14 (14.3)
	Colorectal	13 (13.2)
	Gastric	9 (9.2)
	Other (pancreatic, prostate, renal, hematologic, etc)	36 (36.5)

social and spiritual symptoms and problems, coping strategies, level of adjustment, and level of information and awareness of the illness severity. It included items from tools that had been found to have adequate psychometric properties, according to a systematic review performed for the study's purpose.[20] The totality of items from the following tools was used.

Suffering was measured using the Pictorial Representation of Illness and Self Measure (PRISM) task.[28] It allows for a nondirective and nonverbal quantitative assessment of the suffering experience. It consists of an A4-size white board with a fixed yellow disk in the bottom right-hand corner and a mobile red disk representing the illness. Patients are asked to imagine that the board represents their current life and that the yellow disk represents their self. They are then given the red disk and are asked to place it on the board to represent the place of the illness in their current life. A quantitative measure (the distance between the disks' centers, referred to as self-illness separation [SIS]) is obtained. Scores range between 0 and 27 cm, and a shorter distance denotes more suffering is being experienced.[21] The PRISM has shown great validity and reliability for suffering assessment in a variety of health care settings.[20] A validated version of the original task was used.

Detection of emotional distress (DED) scale is a theory-driven instrument developed to screen for emotional distress

in palliative and end-of-life care.[29] It includes 3 questions directed to the patient which assess the mood state, perceived coping of the situation and concerns, and a record of external signs of emotional distress identified by the clinician. A total score ranging from 0 to 20 was used according to the authors' instructions (sum of the mood state and perceived coping of the situation). Scores ≥9 indicate the presence of emotional distress. The DED was developed for use in Spanish and has demonstrated adequate reliability and convergent validity as well as sensitivity and specificity.[30] Cronbach α was .68.

The Edmonton Symptom Assessment System (ESAS) was used to assess common symptoms in PC patients which included pain, asthenia, nausea, depression, anxiety, drowsiness, shortness of breath, loss of appetite, insomnia, and well-being. It uses a numerical assessment through visual analog scales (VASs) of each symptom.[31] It is a fast, simple, and valid tool frequently used in clinical and research settings.[32] A recently validated version in Spanish was used, indicating an adequate internal consistency with a Cronbach α of .75.[33]

The Structured Interview of Symptoms and Concerns (SISC) was used for the assessment of the presence and severity of common symptoms and concerns in PC such as pain, drowsiness, nausea, weakness/asthenia, dyspnea/shortness of breath, loss of control, loss of dignity, sense of burden, depression, anxiety, loss of interest, hopelessness, desire for death, and suffering. The SISC has shown adequate reliability, concurrent validity, and sensitivity to individual differences.[23] Items can be assessed either using 7-point Likert-type scales or VAS. In the present study, the VAS approach was used to facilitate correlation with the other measures used. A back translation of the items into Spanish was conducted by bilingual researchers and adapted for patient comprehension. Cronbach α of .75 indicated adequate internal consistency. Given that ESAS and SISC share many items, for the study purposes only SISC items not covered by ESAS were used.

The items of insomnia, fear, dysforia, guilt, loss of autonomy, meaning in life, and being at peace from the Scales of Suffering[24] were used. The Scales of Suffering were developed to assess the experience and perception of physical, psychological, and existential suffering in older individuals. They showed high levels of internal consistency, test–retest reliability, and convergent and discriminant validity. A back translation of the items into Spanish was performed.

In addition, other items considered to be relevant for the Latin American context were included, the item of perceived social support from a validated version of the Family APGAR rating system was chosen [34,35] and items examining the concern for the family's future, problems in the neighborhood (such as security issues, access to health resources, etc), and the perceived usefulness of the interview, were generated ad hoc.

Finally, in order to screen for coping strategies, a reduced experimental scale derived from the Coping Strategies Inventory[36] in its Spanish version[37] was used (J. T. Limonero, personal communication). It was comprised of 8 items assessing problem solving, cognitive restructuring, emotional expression, social support, problem avoidance, wishful thinking, self-criticism, and social withdrawal.

Design

Patient selection was performed by 3 PC specialists. Basic information of all invited patients was documented. Reasons for no participation of excluded patients were recorded. Patients that fulfilled inclusion criteria were invited into the study after the PC consultation. If the patient gave his or her consent and the family was comfortable with participation, an appointment was arranged with an independent researcher within 2 weeks from the consultation. All interviews were performed by an experienced and trained clinician in order to maintain an empathic guidance of the interview and expecting a therapeutic effect.[38]

Statistical Analyses

Second-generation statistical techniques were used to model for simultaneous relationships among multiple constructs.[39] Partial least squares-standard error of the mean (PLS-SEM), a variance-based structural equation modeling, was used given its adequacy to test for causal-predictive analysis in situations of high complexity but low theoretical information.[40]

The PLS-SEM is primarily intended to examine complex relationships between latent variables (LVs) or constructs, is less restrictive in terms of sample size, and provides both a measurement model (testing for psychometric quality of indicators) and a structural model.[41-44] It can be used in both exploratory and confirmatory studies. Smart PLS (version 2.0 β) statistical software was used for the data analysis.[45]

The PLS-SEM was performed following the model proposed by Krikorian and Limonero[8] (Figure 1). First, LVs were selected following the theoretical constructs within the model (physical, psychological, social and spiritual dimensions, adjustment problems, coping strategies, and suffering). Then, indicators for each LV were included. Those that reached the .05 significance level using Bootstrapping were retained. Then, the PLS algorithm was performed and indicators with loadings higher than .6 were retained.

Simultaneously, relationships between LV were examined until the best predictive model was obtained. The confidence intervals of the PLS-SEM coefficients were obtained by cross-validation (where results are applied to a new set of observations in order to estimate the parameters). The Q^2 index, which measures the predictive power of the model, was calculated. Significant predictors were selected by maximizing the Q^2 index (cutoff value[41] of $Q^2 > 0$).

Results

Measurement Model Results

Reliability and validity of the measures used for each construct are tested in the measurement model (Table 3). The measures are robust in terms of their internal consistency reliability as
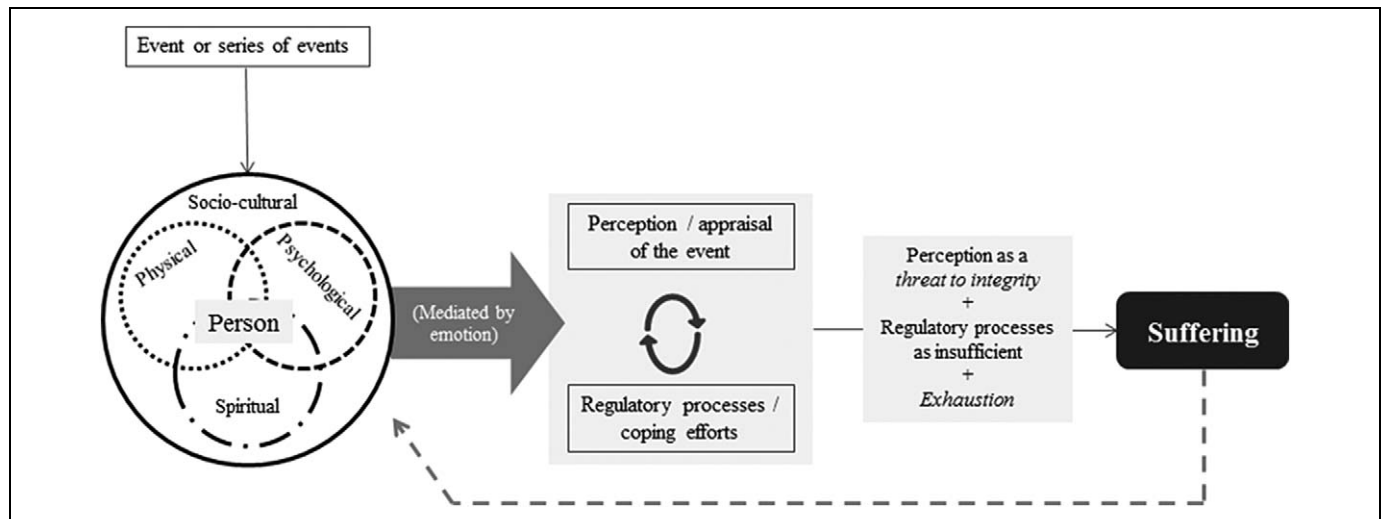
Figure 1. Model of an integrated view of suffering.

Table 3. Assessment of the Measurement Model and Discriminant Validity (Intercorrelations) of the Variable Constructs.

Construct	Items	C	A	SD	PD	PsD	AVE	Composite reliability	Cronbach's α
Coping strategies (C)	3	0.77[a]					0.6	0.81	0.66
Adjustment problems (A)	4	0.62	0.81[a]				0.66	0.88	0.83
Spiritual dimension (SD)	3	0.57	0.57	0.84[a]			0.7	0.88	0.79
Physical dimension (PD)	4	0.46	0.49	0.44	0.76[a]		0.57	0.84	0.75
Psychological dimension (PsD)	4	0.61	0.46	0.56	0.61	0.75[a]	0.57	0.84	0.74
Suffering (S)	2	0.62	0.75	0.62	0.55	0.59	0.7	0.82	0.58

Abbreviation: AVE, average variance extracted.
[a]AVE test values.

indexed by the Cronbach's α and the composite reliability. Particularly, the composite reliabilities of the different measures (considered to be a more conservative measure of reliability[46]) range from .81 to .88, exceeding the recommended threshold value of .70.[47] Also, the average variance extracted (AVE) exceeded .50 for each measure, indicating that at least 50% of the variance of each LV is explained by its contributors.[48]

The elements in the matrix diagonals of Table 3, representing the square roots of the AVEs (AVE test), are greater in all cases than the off-diagonal elements in their corresponding row and column, supporting discriminant validity at the LV level.[41]

The factor and cross-loadings of all indicator items to their respective latent constructs were extracted in order to test for convergent validity. The results indicated that all items loaded on their respective construct from a lower bound of .62 to an upper bound of .88 and more highly on their respective construct than on any other (Table 4). These results support convergent validity at the LV level.[41]

Structural Model Results

The structural model is represented in Figure 2. Suffering levels were determined directly by the components of the psychological dimension and the adjustment problems and indirectly by the components of the physical, psychological, and spiritual dimensions and of the coping strategies.

The influence of the following sociodemographic and clinical variables was controlled for showing no significant contribution to the model: age ($\beta = -.039$; $P > .05$), sex ($\beta = .002$; $P > .05$), education level ($\beta = .011$; $P > .05$), place of residence ($\beta = .036$; $P > .05$), place of interview ($\beta = .019$; $P > .05$), time since diagnosis ($\beta = -.020$; $P > .05$), time since PC ($\beta = -.061$; $P > .05$), and type of cancer ($\beta = .079$; $P > .05$).

The predictive power of the model was tested through the estimation of R^2 values. All R^2 values were greater than .30, and particularly, the explained variance of suffering was .64, indicating a moderate-to-high explained variance of each construct[49] and supporting the model's predictive value.

The impact of each LV on their corresponding dependent LV was examined through the size effect (change in R2). According to the results described in Table 5, the effect size of "spirituality dimension" is low to moderate, while the effect sizes of "psychological dimension" and "coping strategies" are moderate to strong.[50] All β path coefficients are positive in the expected direction and statistically significant at level $P < .01$ (see Figure 2), indicating that they accurately estimate

Table 4. Factor Loading (Bolded) on Each LV and Cross-Loadings.

Factor	Coping strategies	Adjustment problems	Spiritual dimension	Physical dimension	Psychological dimension	Suffering
Asthenia	0.43	0.35	0.28	**0.76**[a]	0.45	0.37
Loss of autonomy	0.31	0.44	0.33	**0.75**[a]	0.49	0.46
Pain	0.27	0.30	0.34	**0.64**[a]	0.38	0.39
Physical distress	0.37	0.41	0.38	**0.86**[a]	0.55	0.46
Mood state	0.53	0.36	0.46	0.59	**0.84**[a]	0.47
Anhedonia	0.37	0.31	0.5	0.27	**0.64**[a]	0.34
Anxiety	0.28	0.30	0.32	0.30	**0.63**[a]	0.41
Depression	0.59	0.41	0.42	0.59	**0.87**[a]	0.52
Desire for death	0.46	0.36	**0.80**[a]	0.33	0.45	0.49
Hopelessness	0.42	0.63	**0.85**[a]	0.39	0.43	0.54
Loss of meaning	0.54	0.44	**0.87**[a]	0.39	0.53	0.53
Perceived coping	0.53	0.77[a]	0.44	0.52	0.43	0.60
Resilience[b]	0.48	**0.80**[a]	0.40	0.22	0.32	0.54
Loss of control	0.50	**0.80**[a]	0.55	0.47	0.40	0.67
Acceptance[b]	0.51	**0.86**[a]	0.46	0.37	0.36	0.65
Wishful thinking	**0.86**[a]	0.60	0.52	0.47	0.53	0.63
Problem avoidance[b]	**0.63**[a]	0.32	0.26	0.14	0.34	0.34
Cognitive restructuring[b]	**0.81**[a]	0.47	0.49	0.39	0.52	0.44
PRISM	0.43	0.56	0.44	0.32	0.38	**0.79**[a]
Suffering VAS	0.6	0.69	0.58	0.57	0.58	**0.88**[a]

Abbreviations: LV, latent variable; PRISM, Pictorial Representation of Illness and Self Measure; VAS, visual analogue scale.
[a] Loadings are greater than .6 and to other loadings in other latent constructs.
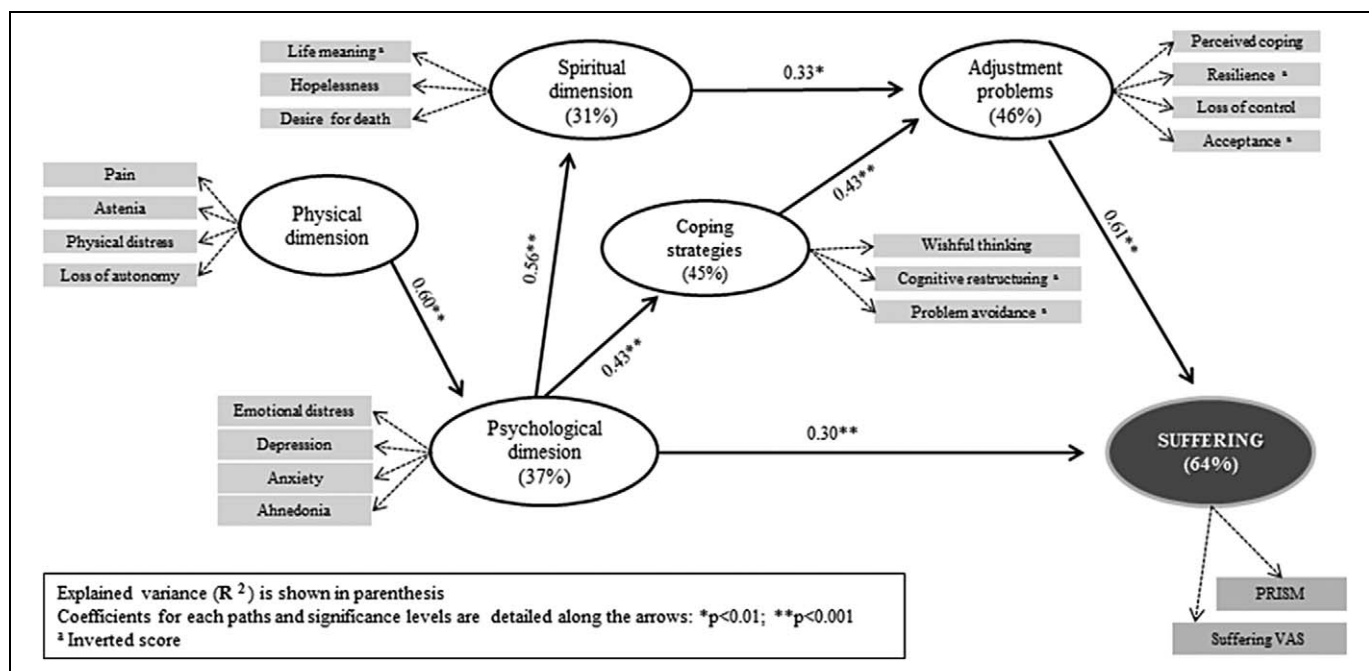[b] Inverted score.

Figure 2. Structural model.

the relationship between the constructs in the population under study.[41]

The Q2 indices exceeded the proposed threshold[41] of Q2 > 0 for each LV, physical dimension (.57), psychological dimension (.56), spiritual dimension (.70), coping strategies (.59),

adjustment problems (.65), and suffering (.70), thus, supporting the predictive value of the model.

Finally, the goodness of fit (GoF) of the model was calculated. It is considered an index of general adequacy of the model as a whole (both in its measurement and structural

Table 5. Effect Sizes of the Structural Model Paths.

LV impact on dependent ones	f2[a]	Impact[b]
Spirituality over coping	0.14	Low to moderate
Spirituality over adjustment	0.14	Low to moderate
Psychological over coping	0.23	Moderate to strong
Coping over adjustment	0.22	Moderate to strong

Abbreviation: LV, latent variable.
[a]Change in R^2.
[b]Values of 0.02, 0.15, and 0.35 are to be considered low, moderate, and strong, respectively.

aspects). The GoF value of the current model was .53, indicating a high predictive value according to Wetzels et al.[51]

Discussion

Regarding the empirical model tested, all the measures used to assess both the indicators and the constructs showed satisfactory levels of reliability, internal consistency, and divergent and convergent validity, supporting the adequacy of the measurement model. In addition, the use of different instruments and measurement scales contributed to reduce the presence of common method bias.[52]

The resulting structural model explained 64% of the variance of the suffering experience in the population under study and more than 30% of the explained variance of each LV. The model showed great adequacy and predictive power both generally and for each path. Therefore, the model accurately reflected the existing relationship between the constructs and their contributions to suffering in this population.

The results of the structural model (Figure 3) indicate that:

- The levels of pain, asthenia, physical distress, and loss of autonomy (physical dimension) have an influence on suffering through the presence of emotional distress indicators (psychological dimension).
- Simultaneously, the levels of anxiety, depression, anhedonia, and altered mood (psychological dimension) predict the level of adjustment problems through the type of coping strategies chosen and the impact on the spiritual dimension.
- At the same time, the influence of the spiritual dimension (hopelessness, desire for death, and loss of meaning in life) on suffering is mediated by the type of coping and the magnitude of the adjustment problems.

Previous studies on the relationship between physical symptoms and suffering show inconsistent results. In some cases, this relationship has been found to be strong, while in others is weak.[13,14,16] This seeming contradiction could be explained using the mediation model presented herein; when physical symptoms cause or accompany emotional distress, although having an impact on other dimensions of the personal experience, they can trigger different levels of suffering.

This approach is consistent with findings from other studies, where the subjective severity of illness and its associated symptoms reliably predict emotional distress.[53-55] Also, evidence has shown that physical and psychological distresses have a strong relationship with spiritual distress.[56,57]

On the other side, the influence of coping strategies and level of adjustment on suffering has been described previously[58-60] as well as the relationship between emotional distress, spiritual distress, and adjustment problems.[58,61-66]

Regarding coping strategies and suffering, the literature findings are inconsistent. This inconsistency is due to discrepancies about how coping is understood and classified,[67-69] and also because individual differences influence not only the choice of a particular strategy but also the way it is employed in each situation.[55,59,70]

In our study, coping strategies such as problem avoidance and cognitive restructuring had an inverse relationship with suffering, while wishful thinking directly contributed to suffering levels. This result is consistent with other findings where patients focusing on the present and on positive aspects of their reality, while seeking to maintain a good mood, declared to have less suffering.[59,60,71] Also, it was found that the relationship between coping strategies and suffering was mediated by adjustment to illness, as was observed previously by Thompson et al.[58]

On the whole, our study supports the proposed theoretical model[8] and also points out the important mediating effect of psychological and spiritual variables between physical symptoms and suffering. Moreover, the similarities between the findings of this study and others conducted on Anglo-Saxon and Latin populations probably reveal the universal and the multicultural features of this integrated view of suffering.

Some limitations of the study should be taken into account. First, its cross-sectional and descriptive design allows for the identification of relationships between variables; although second-generation multivariate analysis suggests predictive–causal relationships, these should be further examined using other methodologies to confirm causality. Second, most variables focused on negative aspects of the illness experience. Future studies should consider the protective role of variables regarding positive aspects such as positive effect, spiritual well-being, resilience, and so on. Third, variables from the social dimension were not retained due to an insufficient contribution to the model. This was probably due to an adequate social and familiar network existence in the population under study. The contribution of social variables should be further examined, especially in populations with less social support as they may have a significant influence on global suffering and should be included in the model.

Clinical Implications

The integrated model of suffering, along with the supporting evidence, has important implications for PC practice:

- It supports the importance of considering the subjective aspects of the suffering experience as well as its person-
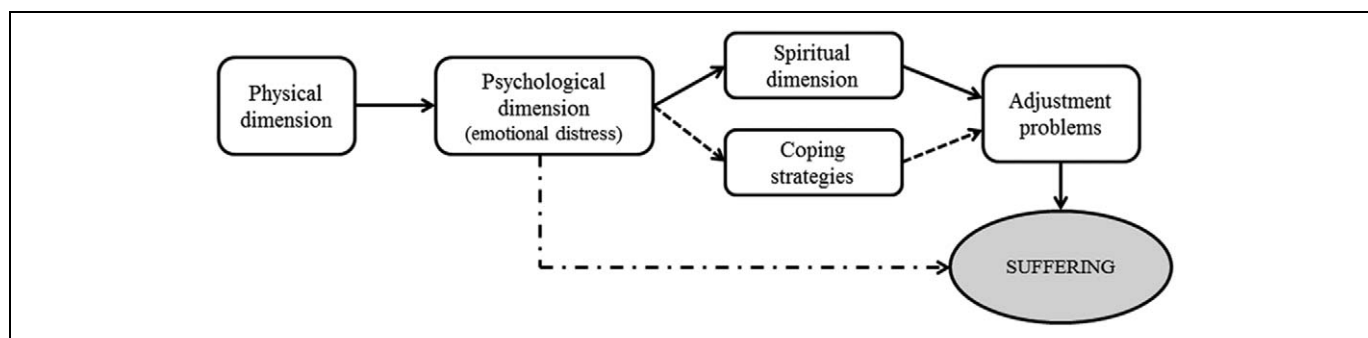
Figure 3. Predictors of suffering in advanced cancer.

related and situational variability.[4,5,7,8,72-74] Consequently, clinicians should not only consider the presence of a problem or its objective correlates but also the meaning given by each particular patient at each particular moment.

- Symptoms or problems of any nature (physical, psychological, and spiritual) have the potential to cause suffering when perceived as threatening and when regulatory processes are insufficient to cope with and to adapt to the circumstances. The current model allows for the intervention of potential sources of suffering using an individualized approach and considering the separate and simultaneous impact of problems in different dimensions. Consequently, problems that may worry the patient should be acknowledged independent of its severity. Also, an approach that helps the identification and potentiation of different coping resources may lead to better outcomes.

- Assessment and interventions should take into account individual differences not only regarding biomedical and sociocultural factors but also including personality characteristics, significance given to the illness, personal resources and coping strategies, and other relevant person-related variables in each clinical encounter.

- Given the close relationship between the physical, psychological, spiritual, and social dimension, treatment plans should be planned considering them equally, simultaneously, and according to the patient's priorities.

- Consequently, suffering relief requires the active presence of a multiprofessional team trained in prevention, early detection, and treatment of problems in all the mentioned dimensions. The need of a team of such characteristics is not only an ethical imperative but also a scientific one in order to offer optimal interventions. Furthermore, an interdisciplinary approach to patient care may better capture the needs of each patient and address them.

- The active participation of professionals from psychosocial and spiritual fields in the PC team is of great importance for suffering relief. Their involvement in a comprehensive manner with biomedical professionals will result in more effective interventions. Also, basic training in psychosocial issues and interventions for medical and nursing practitioners may facilitate early detection and prevention of potential sources of suffering.

- Some particular coping strategies and adjustment problems to the illness constitute predictors of suffering. Therefore, an active involvement of the patient in suffering alleviation is essential as well as all resources in the social context help him or her to adapt to the circumstances. Particularly, guiding the patient into challenging negative views of the illness circumstances and focusing on positive aspects of their experience while helping them accept and adapt to their situation will increase their perceived control.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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