ORIGINAL ARTICLE

Quality of life and spiritual well-being in chronic obstructive pulmonary disease patients

QUALIDADE DE VIDA E BEM-ESTAR ESPIRITUAL EM PACIENTES COM DOENÇA PULMONAR OBSTRUTIVA CRÔNICA

CALIDAD DE VIDA Y BIEN ESTAR ESPIRITUAL EN PACIENTES CON ENFERMEDAD PULMONAR OBSTRUCTIVA CRÓNICA

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ABSTRACT

This study aimed to evaluate health related quality of life (HRQL) and spiritual well-being (SWB) of patients with chronic obstructive pulmonary disease (COPD) and to investigate the relationship between HRQOL and SWB. Seventy outpatients with COPD were interviewed using Portuguese versions of the Seattle Obstructive Lung Disease Questionnaire (SOLDQ) and Spiritual Well-Being Scale (SWBS). SOLDQ domains with lowest and highest scores were Physical Function (37.29±17.19) and Treatment Satisfaction (68.75±28.05). Total score of the SWBS was 94.87±13.56, indicating a moderate level of SWB. Total SWB and the subscale Religious Well-Being correlate positively with Treatment Satisfaction (p=0.007 and p=0.002, respectively). Negative correlation were found between Religious Well-Being and Physical Function domain (r = -0.233, p=0.05). Patients with higher spiritual/religious well-being were more satisfied with treatment and had worst physical functioning.

KEY WORDS

Quality of life.
Spirituality.
Pulmonary disease, chronic obstructive.

RESUMO

Este estudo teve como objetivos avaliar a qualidade de vida relacionada à saúde (QVRS) e o bem-estar espiritual (BEE) de pacientes com doença pulmonar obstrutiva crônica (DPOC) e analisar as relações entre QVRS e BEE. As versões em português do Seattle Obstructive Lung Disease Questionnaire (SOLDQ) e do Spiritual Well-Being Scale (SWBS) foram aplicadas por entrevista a 70 pacientes com DPOC em tratamento ambulatorial. Os domínios do SOLDQ com menor e maior escores foram: Função Física (37,29±17,19) e Satisfação com o Tratamento (68,75±28,05). O escore médio de 94,87±13,56 indica um nível moderado de BEE. O escore total do SWBS e o da subescala Bem-Estar Religioso correlacionaram-se positivamente com o domínio Satisfação com o Tratamento (p=0,007 e p=0,002, respectivamente). Correlação negativa foi encontrada entre Bem-Estar Religioso e Função Física (p=0,05). Pacientes com maior bem-estar religioso estavam mais satisfeitos com o tratamento e tinham pior funcionamento físico.

DESCRITORES

Qualidade de vida.
Espiritualidade.
Doença pulmonar obstrutiva crônica.

RESUMEN

En este estudio se evaluaron la calidad de vida relacionada con la salud (CVRS) y el bienestar espiritual (BEE) de pacientes con enfermedad pulmonar obstructiva crónica (EPOC) y además la relación entre la CVRS y BEE. Setenta pacientes con EPOC en tratamiento ambulatorial fuerón entrevistados usando las versiones en portugués del Seattle Obstructive Lung Disease Questionnaire (SOLDQ) y del Spiritual Well-Being Scale (SWBS). Las dimensiones del SOLDQ con puntuaciones más bajos y más altos fueron: Función Física (37,29 ± 17,19) y Satisfacción con el Tratamiento (68,75 ± 28,05). La puntuación media 94,87 ± 13,56 indica un nivel moderado de BEE. La puntuación total del Bienestar Religioso correlacionó positivamente con la Satisfacción con el Tratamiento (p = 0,007 y p = 0,002, respectivamente). Se encontró correlación negativa entre bienestar religioso y función físico (p = 0,05). Los pacientes con mayor bienestar religioso estaban más satisfechos con el tratamiento y tenían peor función físico.

DESCRIPTORES

Calidad de vida.
Espiritualidad.
Enfermedad pulmonar obstructiva crónica.

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INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) affected, in 2004, 15.8% of the population over 40 years of age in the metropolitan region of São Paulo, a prevalence deemed rather high considering the disease's morbidity and mortality [1].

The COPD can be characterized as a pathological state where air flow is limited and which is not completely reversible. This limitation is usually progressive and associated to an abnormal pulmonary inflammatory response. The associated risk factors may be both environmental and behavioral and how much an individual is susceptible and the disease usually results from an interaction among these factors[2]. The disease has an irreversible and incurable nature and interferes broad and complexly with all the areas in life. Factors such as shortness of breath, intolerance to physical activity, coughing frequency, palliative treatment, difficulty in facing the limitations imposed by the disease, dependence on the family, anxiety and depression and finally the consequent perspective of the proximity of death may compromise patients' quality of life [3-4] in various degrees.

In the healthcare area the concept of Health-Related Quality of Life (HRQL) has been used to refer to the subjective perception of the aspects of life that are directly influenced by alterations in the health or those affected by the disease and its treatment [5].

In extreme circumstances, such as in case of a serious or incapacitating disease, many people tend to rely on beliefs and religious and spiritual practices, looking for relieving the stress and to keep a sense of control and hope when facing the situation[6]. The focus of spirituality is oriented towards beliefs and a relation with a higher power, matters related to the objective and meaning of life, whether or not including beliefs and religious practices [7].

Increasing evidence of the positive relation between spirituality/religiosity and physical and mental health has been documented in the literature.

The complexity of the spirituality concept makes measuring it also complex. Spiritual Well-Being, i.e., the perception of how religious/spiritual beliefs enable a patient to fell well [7] is one of its aspects that can be assessed. Measurement tools of spiritual well-being, such as the Spiritual Well-Being Scale, have been developed based on a concept that includes a vertical component, the religious one (meaning well-being related to God); and a horizontal component, the existential one (sense of purpose and satisfaction in life), where the latter does not imply any reference to any specifically religious content [7].

Increasing evidence of the positive relation between spirituality/religiosity and physical and mental health has been documented in the literature[8]. Although several factors are related to the HRQL of patients with COPD[3-4], the influence of the spiritual dimension has not been often studied in this population.

OBJECTIVES

The objectives of the study were to assess the HRQL and the spiritual well-being of individuals suffering from COPD and to analyze the relations between both constructs in this clientele.

METHOD

This is a cross-sectional descriptive study conducted with outpatients diagnosed with COPD, of both genders, who had been treated in the Ambulatory Ward of Pneumology of Hospital das Clínicas of the Medical School of the University of São Paulo for at least six month in cognitive and mental conditions to answers to the research tools and who agreed to participate in the study by signing a Free and Informed Consent. The project was approved by the Commission of Ethics in Research of the institution (Protocol no. 0295/08) and by the Nursing School of the University of São Paulo (Procedure no. 719/2008).

To collect data three instruments were used. A Socio-Demographic and Clinical Characterization Chart of the patients including: gender, age, occupation, marital status, education, religion, religious practices, smoking habits, how long patients had suffered from COPD, pulmonary function and seriousness of the disease - classified as light, moderate, serious and very serious according to the GOLD international standard[2].

The second instrument was the Seattle Obstructive Lung Disease Questionnaire (SOLDQ)[9], in its adapted and validated version in Portuguese[10]. It is composed of 29 items distributed into seven specific questions to assess the HRQL of patients with COPD. The items are grouped in four domains: Physical Function (it measures the degree of dyspnea and extension of physical limitation); Emotional Function (it evaluates the impact of the disease on psychological well-being); Coping Capacity (it measures self-efficacy, which mirrors patients' conviction of their capacity of reaching some results); and Treatment Satisfaction (it assesses patients' level of satisfaction with the care received specifically related to their pulmonary disease). The scores attributed to the items in each domain are summed and the gross results gotten are converted into a scale from 0 to 100, where the highest scores represent better HRQL[9-10].

The third instrument used was the Spiritual Well-Being Scale (SWBS), in its version adapted to Portuguese[7]. Deemed a reference to measure spirituality, it is composed of 20 items distributed into two domains: Religious Well-Being (vertical domain of communion and personal relation with God or a higher power) and Existential Well-Being (horizontal domain related to satisfaction and mean-

ing of life)[7]. The scores may vary from 10 to 60 for each dimension and when summed they result in the total score of Spiritual Well-Being, which may vary from 20 to 120 points. The intervals from 20 to 40, from 41 to 99 and from 100 to 120 are suggested respectively for low, moderate and high Spiritual Well-Being; and from 10 to 20 (low), from 21 to 49 (moderate) and from 50 to 60 (high) for the dimensions[7, 11].

The outpatients were invited to join the study on the dates scheduled for their visits to the ambulatory ward and they were interviewed by the first author at a specific place in the ambulatory ward, usually after their visit to the doctor.

Descriptive statistics was used to characterize the sample related to socio-demographic and clinical scores and to the scores in the SOLDQ and SWBS instruments. The Kolmogorov-Smirnov test showed that only the scores in the *Treatment Satisfaction* domain failed to present normal distribution (p=0.040). In the correlation between the SOLDQ and the SWBS, the Spearman test was applied to this domain and the Pearson test to the others. The reliability of the HRQL measurements and those of Spiritual Well-Being (SWB) for the study's sample was analyzed according to internal consistence of items and domains by using the Cronbach's alpha coefficient (scores =0.60 were considered acceptable)[12].

RESULTS

The characteristics of the 70 patients in the study are presented in Table 1.

Table 1 - Socio-demographic and clinical characteristics of patients with COPD - São Paulo - 2008.

Variables	N	%
Gender		
Male/Female	42/28	60.0/40.0
Current occupation		
Yes/No	9/61	12.9/87.1
Marital status		
With a life partner	50	71.4
Without a life partner	20	28.6
Education		
Illiterate	11	15.7
Primary school	46	65.7
High school and college	13	18.6
Religion		
Catholic	47	67.1
Evangelical Churches	15	21.4
Spiritism/voodoo rites	8	10.4
Religious practice		
Yes/No	61/9	87.1/12.9
Associated diseases		
Yes/No	38/32	54.3/45.7
Ex-smokers		
Yes/No	57/13	81.4/18.6
Degree of COPD		
Light/moderate	23	32.9
Serious/ very serious	47	67.1

	Mean	Standard deviation	Median	Minimum	Maximum
Age	64.24	10.22	65.00	43.00	81.00
Monthly family income	1129.10	891.79	900.00	280.00	5000.00
Monthly per-capita income (R$)	486.09	424.53	375.00	75.00	2500.00
Time with COPD (years)	9.17	5.89	7.50	1.00	20.00
Time of smoking (years)	31.04	15.46	31.00	0.00	61.00
VEF1 (%)	44.81	14.33	42.00	19.00	80.00

The data in Table 1 show that the sample was predominantly composed by men (42/60.0%), old people (64.24±10.22 years), with low per-capita income (R$ 486.09 on average) and low level of schooling (46/65.7% attended primary school), currently unemployed (61/87.1%) and facing a serious or very serious condition (47/67.1%). In addition to the COPD, 38 participants (54.3%) reported other associated diseases: arterial hypertension (29/67.4%) being the most frequent. The significant majority of the patients (61/87.1%) reported to attend some religious activities. Out of a total of 87 quotes, praying was mentioned 45 times (51.7%), attending the mass 39 (44.8%) and reading the Bible 3 times (3.4%).

The data in Table 2 show that in the SOLDQ instrument the Physical Function domain was the one with the lower mean score (37.29) and the Treatment Satisfaction domain got the highest score (68.75). As to the SWBS, the total 94.87 places the patients in the moderate level of Spiritual Well-Being; for the dimensions, a degree of Religious Well-Being (51.50) was obtained higher than that of Existential Well-Being (43.37).

Except for the Emotional Function domain, whose alpha coefficient was just 0.53, all the others were measured with acceptable reliability.

Table 2 - Descriptive statistics of the SOLDQ (domains) and SWBS scores (total and domains) and the Cronbach's alpha coefficients - São Paulo - 2008

SOLDQ	Mean (s.d.)	Median	Minimum	Maximum	Cronbach's Alpha
Physical Function	37.29 (17.19)	35.53	5.26	81.58	0.91
Emotional Function	61.38 (20.41)	60.00	16.67	100.00	0.53
Ability of Coping	63.99 (20.19)	66.67	16.67	100.00	0.61
Treatment Satisfaction	68.75 (28.05)	75.00	0.00	100.00	0.84
SWBS					
Spiritual Well-Being (total)	94.87 (13.56)	96.00	64.00	119.00	0.83
Religious Well-Being	51.50 (8.68)	54.00	24.00	60.00	0.86
Existential Well-Being	43.37 (6.76)	42.50	27.00	59.00	0.60

In Table 3 the data indicate that the Spiritual Well-Being and Religious Well-Being dimensions had positive and significant correlations with the Treatment Satisfaction domain (p=0.007 and p=0.002, respectively). There was inverse and significant correlation between Religious Well-Being and Physical Function (p= 0.05).

Table 3 - Correlation between the SOLDQ and SWBS scores - São Paulo - 2008

SWBS	SOLDQ			
	Physical Function	Emotional Function	Ability of Coping	Treatment Satisfaction
Spiritual Well-Being	-0.102 (p=0.40)	0.067 (p=0.58)	-0.047 (p=0.69)	0.322 **(p=0.007)**
Religious Well-Being	-0.233 **(p=0.05)**	-0.063 (p=0.60)	-0.182 (p=0.13)	0.367 **(p=0.002)**
Existential Well-Being	0.094 (p=0.44)	0.215 (p=0.07)	0.139 (p=0.25)	0.168 (p=0.17)

DISCUSSION

In this study we can highlight that patients' physical function was severely compromised 37.29±17.19) in the evaluation of the HRQL, which is compatible with the level of seriousness of the COPD presented by the patients (67% were classified at III and IV degrees of seriousness of the disease). They also had a moderate level of spiritual well-being with more significant contribution of the religious component than of the existential one, mentioning more than a religious practice per patient, mainly related to prayers and mass attendance.

The impact of the COPD on physical function in the SOLDQ can be compared to that obtained in the original study of the development of the instrument[9], 34.46, and also in the Brazilian validation[10], where the mean was 46.8. The items that contributed the most with the low scores in this function were those related to limitations to

more vigorous activities and those measuring the degree of limitation caused by shortness of breath.

The highest mean reached in the Treatment Satisfaction domain (68.75) is also similar to that found in the original study of validation of the instrument[9], i.e., 68.98 for patients with unstable COPD.

Previous studies[13-14] have related the satisfaction of patients with COPD with the healthcare providers' communication and interpersonal skills. Patients well oriented as to the treatment and their health problems seem more satisfied and this increased satisfaction can result in more compliance with guidelines. Additionally, the support received may lead to positive emotional responses and stimulate the capacity of facing the disease, which also affects the level of satisfaction. A research[13] involving about 16,000 patients with chronic diseases, 4,418 with COPD among them, found out that increased satisfaction with the healthcare provided was significantly associated to educational background, to patients' coping capacity and knowledge of the disease, even without any improvements in symptoms.

In this study, spiritual well-being showed to be more related to the feeling of communion with God or a higher power than with existential issues of accomplishment, sense and meaning in life, considering the higher score gotten in the religious dimension of the specific instrument. The same result has been found in studies using the SWBS in patients with breast cancer[15] and in students with minor psychiatric disorders[11]. However, another study[7] has found means very close to both components, existential (45.61) and religious (45.10), among medical and law students, suggesting differences among populations with or without clinical problems as to the degree of valuation of religious or existential aspects. It is possible that religion is a resource more used by people who are sick than by healthy people[16].

Patients' satisfaction with the treatment received was positive and significantly correlated to Spiritual and Religious Well-Being. This result may be related to certain characteristics, such as generosity and gratitude, usually more often found in people with some religious or spiritual orientation[17] such as those in this study.

Before a situation of disease and incapacity, patients tend to develop greater attachment to religious beliefs in their search for comfort and support from a higher power, thus confirming not only the previous results, but also the correlation between the levels of religious well-being and low physical capacity. This role of the religion has been reported by several authors[17-19] who, however, acknowledge that religious beliefs can also bring negative consequences when people start to rely on the intervention of a higher power and excuse themselves from the responsibility related to life's requirements.

We could say that an additional contribution of the study was the use of the instruments Seattle Obstructive Lung Disease Questionnaire and Spiritual Well-Being Scale, which showed acceptable reliability to measure the HRQL and Spiritual Well-Being of patients suffering from COPD considering the high values of the Cronbach's alpha coefficient obtained. They still are instruments infrequently used in our environment which need to be tested in other studies.

This study's potential limitations should be considered, such as the research's cross-sectional design which does not allow setting temporal relations between the measurements explored and the results in the health. It was not possible either to include a higher number of patients with light COPD related to those in a more serious situation given the characteristics of the healthcare facilities where the study was conducted. Additionally, the influence of factors such as patients' personal and clinical characteristics in the relations found was not assessed. New researches should be done with different methodological designs and larger samples in order to deepen the understanding of the processes through which spirituality and religiosity influence the health and quality of life of people suffering from chronic diseases, such as those included in this study. Studies on these themes are particularly relevant in a country where religiosity is a strong characteristic and where there is a diversity of religious and spiritual beliefs which in some way can influence the health of the population.

CONCLUSIONS

In this study the Physical Function has to be highlighted as the most compromising dimension of the HRQL of the patients studied and the religious dimension had a more important participation than the existential one in spiritual well-being. We also verified a inverse and significant correlation between religious well-being and physical function, and a positive and significant correlation between spiritual well-being and its religious component with the treatment satisfaction domain.

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