Chronic Obstructive Pulmonary Disease Patient Well-Being and Its Relationship with Clinical and Patient-Reported Outcomes: A Real-Life Observational Study

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Key Words

Patient well-being • Chronic obstructive pulmonary disease • Quality of life • Dyspnoea • Illness perception • Alexithymia

Abstract

Background: Quality of life is an umbrella concept that refers to all aspects of a person's life, including health status and well-being. While health status measure focuses on the impact of the disease on physical functioning, well-being represents the self-representation of the emotional states related to the disease itself. **Objectives:** The objective of this study was to evaluate the psychological well-being and its determining factors in a real-life chronic obstructive pulmonary disease (COPD) population and to evaluate if patients with a different well-being differ in illness perception, health status and alexithymia. **Methods:** Psychological well-being (Psychological General Well-Being Index), health status (SF-36), illness perception (Illness Perception Questionnaire), alexithymia (Toronto Alexithymia Scale), as well as clinical parameters were assessed in COPD out-patients. **Results:**

One hundred and sixty-four patients, with a mean forced expiratory volume in 1 s of 58.5%, were recruited. Forty percent of them had a moderately/severely impaired well-being, not correlated with forced expiratory volume in 1 s and the Charlson index value but significantly with the Medical Research Council score ($p = 0.0001$) that appeared to be the dominant factor. Patients with impaired well-being showed a different illness perception in terms of correct identification of symptoms, disease consequences, emotional representation and confidence in treatment compared with those having a positive well-being. The latter presented a lower alexithymia prevalence and a better health status. **Conclusions:** In order to minimize the disease-negative effects on patients' lives, assessment of well-being and its determining factors, as well as planning specific behavioural, educational and therapeutic interventions seem to be relevant and useful.

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Introduction

In chronic respiratory pathologies, the patient's subjective experience is increasingly investigated.

Health-related quality of life (HRQoL), namely the impact of the disease and its therapy upon a patient as perceived by the patient himself [1], has been widely explored in chronic obstructive pulmonary disease (COPD) [2–9].

HRQoL is a broad-ranging concept incorporating, in a complex way, the person's physical and mental health, level of independence, social relationships, well-being and satisfaction [10, 11]. Due to its multidimensional nature, HRQoL can be approached from different angles. In COPD clinical research, attention has been mainly reserved to health status which is a component of HRQoL that focuses on perceived health in terms of the ability to function in physical, emotional and social activities [12–14]. On the contrary, very little attention has been paid to the patients' internal experiences, like for example to well-being, which is the self-representation of affective or emotional states [15]. In fact, very few studies explored this component of HRQoL in COPD patients by means of validated tools [16, 17].

Well-being is subjective and is a relative, rather than an absolute, concept. The reference point for judging well-being is the individual's own aspirations, based on a blend of objective reality and their subjective reactions to it. Subjective well-being depends on how the health status is perceived through filters of cognitive and emotional judgment and of personality [18]. For these reasons, in exploring well-being in COPD patients, we took into account its relationship with both the patient's perspective on the disease and the patient's personal characteristics, analysing illness perception and alexithymia, respectively.

The term 'illness perception' refers to the personal model or representation of an illness, aimed at giving a sense and a response to the presence of a disease [19]. The role of the patient's illness beliefs has been observed to strongly influence both help-seeking behaviour and treatment outcome [20, 21].

Alexithymia is an individual characteristic implying difficulties in identifying and expressing feelings and in differentiating between emotions and bodily sensations [22]. Recent research has suggested that alexithymia can be considered as a possible risk factor for a variety of medical conditions [22] as it may increase susceptibility to disease development and may influence health outcomes [23–25].

Individuals with alexithymia present an impaired ability to build mental representations of emotions, and there-

fore, they misinterpret physical symptoms of emotional arousal as symptoms of somatic disease [26]. Alexithymia is not an all-or-none phenomenon, but it is considered as a personality trait normally distributed in the general population, where the prevalence range is 5–13% [27, 28].

The aim of the study was to compare the psychological well-being of COPD patients with that of the general population, to explore which clinical variables determine well-being and to evaluate if patients with different levels of well-being differ in health status, illness perception and personal traits such as alexithymia.

Materials and Methods

COPD patients, treated according to GOLD (Global Obstructive Lung Disease) guidelines, attending the Allergy and Respiratory Diseases Clinic at the University of Genoa for a follow-up visit in the period from July to September 2009 were asked to participate in the study. Comprehension of written and spoken Italian, availability to participate in the study, as well as clinical and spirometric patterns of COPD in accordance with the GOLD guidelines [29] were adopted as inclusion criteria.

The enrolment excluded patients with impaired cognitive functions, visual-auditory deficits, physical inability to fill in the questionnaires without any help and patients with uncontrolled severe concomitant diseases.

This study was performed according to the Good Clinical Practice standards, the Declaration of Helsinki and was approved by the local ethics committee. All patients included in this study gave written informed consent.

Once written informed consent to participate in the study was achieved, the patients waiting for their follow-up visit were invited by the nursing staff to fill in validated questionnaires, in order to investigate well-being, illness perception, health status and alexithymia.

The Psychological General Well-Being Index (PGWBI) [16], a tool developed to provide an index of subjective well-being or distress, was adopted. The PGWBI focuses on the important dimension of psychological general well-being and does not include the evaluation of physical health. It consists of 22 self-administered items, rated on a 6-point scale, which assess psychological and general well-being in 6 domains: anxiety, depressed mood, positive well-being, self-control, general health and vitality. Each item has 6 possible answer scores (from 0 to 5) referred to the last 4 weeks. Each domain is defined by a minimum of 3 or a maximum of 5 items. The scores for all domains are summarized in a global score, which reaches a maximum of 110 points, representing the best achievable well-being. In accordance with questionnaire developers, the results can also be grouped according to the well-being level into: positive well-being (score ≥ 96), no distress (≥ 73 and ≤ 95), moderate distress (≥ 60 and ≤ 72) and severe distress (< 60) [30].

The Illness Perception Questionnaire (IPQ-R) [19] assesses people's beliefs and understanding of their illness. It is divided into 2 parts. The first part constitutes the identity factor, describes the presence of symptoms complained by the patient during the disease

as well as the identification, by the patient himself, of the potential link between each of these symptoms (pain, sore throat, nausea, fatigue, weight loss, stiff joints, sore eyes, breathlessness, headache, upset stomach, sleep disturbances, dizziness and loss of strength) and the disease. The second part of the IPQ-R investigates the following items: consequences, timeline acute/chronic, timeline cyclical, coherence, personal control, treatment control and emotional representation. The questionnaire, applicable to all disease conditions, does not have a cutoff or a normal reference value, but it is analysed through the comparison between groups [19].

The SF-36 is a multi-purpose, short-form health 36-item questionnaire. It yields an 8-scale profile referring to 8 health concepts: physical functioning, role limitations due to physical health problems, bodily pain, social functioning, general mental health, role limitations due to emotional problems, vitality and general health perceptions. The SF-36 scores can also be aggregated in a physical component summary and a mental component summary, used in this study [31].

The Toronto Alexithymia Scale (TAS-20) is composed of 20 items rated on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). It has a 3-factor structure congruent with the alexithymia construct: difficulty in identifying feelings, difficulty in describing feelings, and externally oriented thinking. The results are expressed as 3 factorial scores and a global score. The TAS-20 global score ranges from 20 to 100; subjects scoring ≥ 61 are considered alexithymic, those between 51 and 60 borderline, while those scoring < 51 are considered non-alexithymic [32].

The filled-in questionnaires were asked back to the nursing staff when patients were called for their visit. History, smoking habit, spirometry, according to the European Respiratory Society [33, 34], Medical Research Council (MRC) score [35] and Charlson index [36], were collected during the medical visit.

Statistical Analysis

A descriptive analysis of the population was performed. PGWBI scores were dichotomized considering the status of well-being or the presence/degree of distress. PGWBI scores of COPD patients were compared to PGWBI scores of an Italian reference population of the same age (65–74 years) by means of the Z test.

In order to investigate if patients reaching well-being (PGWBI scores ≥ 73) had different scores compared to those with moderate/severe distress (PGWBI scores < 73) concerning illness perception, health status and alexithymia level, the Student t test was performed.

A univariate analysis with the χ^2 test to assess dichotomic answers of identity factor questions was adopted.

A regression analysis was performed to assess the relationship between the variable 'outcome' (PGWBI) and the explanatory variables associated with it, including MRC score, Charlson index and forced expiratory volume in 1 s (FEV₁).

Results

One hundred and sixty-four patients with a mean age of 73.4 years (SD 8.59), an average FEV₁ of 58.50% predicted (SD 21.46) and a Charlson weighted index of co-

Table 1. Demographic and clinical characteristics (n = 164)

		n
Gender	male	119 (72.6)
	female	45 (27.4)
Smoking	current smoker	29 (17.7)
	former smoker	135 (82.3)
Education	primary	76 (46.3)
	secondary school	42 (25.4)
	high school	37 (22.8)
	academic degree	9 (5.5)
GOLD stage	mild	28 (17.1)
	moderate	71 (43.3)
	severe	44 (26.8)
	very severe	21 (12.8)
MRC score	1	38 (23.0)
	2	40 (24.4)
	3	28 (17.0)
	4	24 (14.8)
	5	34 (20.7)

Figures in parentheses are percentages.

morbidity of 2.88 (SD 1.74) were recruited. Demographic and clinical data are shown in table 1. In accordance with the stratification of the PGWBI score, 32.9% of the population had a positive well-being, 27.1% distress absence, 37.1% moderate distress and 2.9% severe distress. Compared to the Italian reference population aged between 65 and 74 years [30], COPD patients had a comparable PGWBI total score, although they showed significantly worse scores in vitality ($p < 0.0001$) and general health ($p < 0.0424$). Pearson correlation showed that the total PGWBI score was not correlated with FEV₁ ($r = 0.162$; $p = 0.060$) and Charlson weighted index of comorbidity ($r = -0.67$; $p = 0.434$), while a significant correlation was found with the MRC score (Spearman correlation $r = -0.466$; $p = 0.0001$; fig. 1). Stepwise regression analysis, addressed to show which among the clinical variables (FEV₁, Charlson index and MRC score) was the most relevant in determining the well-being, showed that the dyspnoea score was the dominant factor (test $F = 25.3$; $p = 0.0001$; condition index MRC score = 4.105).

SF-36 physical and mental component scores were 35.64 (SD 11.07) and 44.99 (SD 11.79), respectively. The TAS-20 total score was 54.31 (SD 18.76), with 32.9% of alexithymic subjects.

The comparison between patients with well-being status (PGWBI scores ≥ 73) and patients with moderate/severe distress (PGWBI scores < 73) concerning clinical

Fig. 1. Correlation between the PGWBI total score and the MRC score ($r = -0.466$, $r^2 = 0.217$).

data, IPQ-R, SF-36 and TAS-20 showed significant differences that are reported in table 2. Concerning the identity factor, distressed patients complained of more pain ($\chi^2 = 9.561$, $p = 0.002$), nausea ($\chi^2 = 5.606$, $p = 0.027$), weight loss ($\chi^2 = 7.911$, $p = 0.006$), breathlessness ($\chi^2 = 6.991$, $p = 0.014$), headache ($\chi^2 = 6.225$, $p = 0.014$), sleep disturbances ($\chi^2 = 5.558$, $p = 0.023$), dizziness ($\chi^2 = 5.588$, $p = 0.027$) and loss of strength ($\chi^2 = 10.244$, $p = 0.002$). When compared with subjects without distress, distressed patients more frequently ascribed the following symptoms to COPD: pain ($\chi^2 = 11.736$, $p = 0.006$), weight loss ($\chi^2 = 5.325$, $p = 0.026$), breathlessness ($\chi^2 = 5.069$, $p = 0.037$), dizziness ($\chi^2 = 4.600$, $p = 0.039$), and loss of strength ($\chi^2 = 7.161$, $p = 0.009$).

Discussion

Objective and subjective methods are needed to understand a disease thoroughly. This was foreshadowed by the World Health Organization 1948 definition of health in terms of 'physical, mental and social well-being, and not merely the absence of disease and infirmity' [37]. Well-being is now commonly evaluated as outcome measure as it reflects the expanded goals of treatment, from medical treatment toward broader health care. Interest in the nature of psychological well-being has grown over the past 15 years, and major advances have been made. The importance of this topic has been high-

lighted by studies that link well-being to physiological changes, to enhanced coping with health changes [38] and even to reduced mortality [39]. The aim of the study was to analyse well-being in a COPD population in a real-life setting. The results showed that an impaired well-being is present in almost 40% of patients. Since reference values on healthy subjects for this age group are not available, we cannot definitely ascribe this evidence to the disease exclusively. In this regard, we have performed a comparison with subjects of similar age randomly selected from the electoral rolls and independently from their health status. Compared with this group, the patients afferent to a medical visit for COPD had an impaired well-being in terms of less vitality and perceived their general health as worse. In other words, COPD patients, compared with a group of subjects of the same age, feel more tired, strained, weak and report more concerns about their health, more limitations and physical ailments.

Since PGWBI targets people's self-representations of aspects concerning their general well-being, the low correlation with some clinical indexes shown was expected [40].

The relevance of dyspnoea in determining well-being makes it the fundamental treatment target. Independently from age and pulmonary function, patients with a positive well-being presented a clearer idea concerning the symptoms effectively related to COPD; moreover, they considered their disease and its consequences less serious, also from an emotional viewpoint, they were more confident about the treatment and they perceived the disease as less cyclical and less chronic. They also reported a better physical and mental health status and showed a greater ability to distinguish between physical and emotional perceptions and to express them.

Therefore, the patient's well-being is not only influenced by his/her health status. Individual illness perception, which depends both on the patient's personality traits and on the way he/she is informed about the disease, which can be partially modifiable, should be considered. Moreover, other elements, such as alexithymia and a relatively stable personality trait, should be taken into account because they can influence the patient's symptom perception and modulate the subjective evaluation of the symptoms themselves (i.e. with the dyspnoea questionnaire). Alexithymic patients do not tend to adopt nuances in describing and discriminating feelings and they are more likely to express themselves in terms of bodily symptoms. This proneness towards increased somatic symptom reporting, that does not depend on the

Table 2. Clinical parameters, illness perception, health status and alexithymia comparison between patients with well-being status (PGWBI scores ≥ 73) and patients with moderate/severe distress (PGWBI scores < 73)

	PGWBI scores ≥ 73	PGWBI scores < 73	Significance (2-tailed)
Age, years	72.53 (7.66)	73.51 (9.63)	
FEV ₁ , % predicted	60.29 (18.49)	56.46 (23.72)	0.314
Charlson index [1–8]	2.40 (1.42)	3.07 (1.83)	0.022*
MRC score [1–5]	2.27 (1.33)	3.36 (1.45)	0.001*
IPQ-R identity [0–14]	3.84 (2.60)	5.48 (2.83)	0.001*
IPQ-R timeline [0–30]	18.81 (5.81)	20.75 (5.28)	0.033*
IPQ-R consequences [0–30]	15.72 (4.77)	19.46 (5.48)	0.001*
IPQ-R personal control [0–30]	17.10 (4.78)	14.97 (5.24)	0.220
IPQ-R treatment control [0–30]	15.69 (3.97)	13.59 (4.40)	0.015*
IPQ-R illness coherence [0–30]	12.99 (4.33)	11.60 (4.68)	0.119
IPQ-R timeline cyclical [0–24]	11.11 (4.10)	12.30 (4.50)	0.016*
IPQ-R emotional representations [0–30]	15.75 (5.87)	18.41 (6.31)	0.001*
SF-36 PCS [0–100]	39.69 (10.03)	29.04 (9.44)	0.001*
SF-36 MCS [0–100]	47.41 (10.71)	41.05 (12.46)	0.001*
TAS-20 total score [20–100]	43.54 (16.47)	61.01 (17.12)	0.001*

Data are means, with SD in parentheses. Figures in brackets are ranges. PCS = Physical component summary; MCS = mental component summary. * Statistically significant.

COPD severity, may be reflected in a poorer well-being. Therefore, a low well-being level can depend on specific difficulties of the patient in dealing with his/her health problems.

A comprehensive assessment of the effects of COPD requires the evaluation not only of lung function and symptoms, but also of the overall burden of the disease on everyday functioning and emotional well-being [41]. Assessing a patient's psychological well-being with standardized methods can provide useful information to recognize those patients who, independently from their severity degree, hardly cope with COPD. In this way, it is possible to perform an overall assessment of the patient at baseline and monitor the treatment effect at several levels. The aim is to plan, when necessary, specific and personalized interventions in order to improve the pa-

tient's management (i.e. educational programs, psychological support, involvements of family or other caregivers).

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The authors declare that they have no conflicts of interests.

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