Identifying COPD patients at risk for worse symptoms, HRQoL and self-efficacy: A cluster analysis

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ABSTRACT

Objectives: To identify clusters of chronic obstructive pulmonary disease (COPD) patients with distinct beliefs about their illness in terms of symptoms, health-related quality of life (HRQoL), self-efficacy and daily life physical activity (DLPA). **Methods:** This cross-sectional study included 150 COPD outpatients. The patients' illness perceptions, clinical control, HRQoL, self-efficacy and DLPA (accelerometry) were evaluated. A cluster analysis was conducted using data from the Illness Perceptions Questionnaire - Revised to establish groups of patients with distinct illness perceptions. Differences between clusters were tested using a T-test or a Mann-Whitney U test. **Results:** The cluster analysis revealed two groups: distressed (n=95) and coping (n=55). Despite the fact that both clusters presented similar pulmonary function, between-cluster differences were observed in their self-efficacy, dyspnea, HRQoL, clinical control ($p<0.001$) and educational level ($p=0.002$). The levels of DLPA did not differ between the clusters. **Discussion:** We observed that clinically stable COPD patients who displayed higher emotional representations and less coherence had heightened symptoms, poorer HRQoL, worse self-efficacy and lower educational levels. These results emphasize the need to routinely evaluate illness perceptions in

COPD patients to target and tailor the proper treatment to improve these important health outcomes.

keywords: COPD, illness perceptions, health-related quality of life, self-efficacy, dyspnea

INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is characterised by chronic airflow limitation which is not fully reversible [1]. The restricted ability to perform activities of daily living and the fear of becoming breathless may lead to psychological co-morbidities including symptoms of anxiety and depression [2]. It is known that the manner in which patients with chronic illness perceive their disease significantly influences their perceived symptoms, functioning and health-related quality of life (HRQoL)[3]; therefore, illness perceptions (IPs) are considered an important psychological factor that can influence many relevant clinical outcomes.

The 'Common Sense' model (CSM) proposed by Leventhal et al. addresses how IPs (the manner in which people perceive their disease) influence coping behaviours and health outcomes associated with illness [4]. According to the CSM, patients construct their own IPs based on appraisals of their clinical condition and symptoms, providing a basis for a coping response. Personal illness models comprise nine domains: identity, consequences, control (personal and treatment), timeline (acute/chronic), timeline cyclical, coherence, emotional representation and causal domain. In most studies, the association

between IPs and clinical outcomes has been evaluated and analysed independently using a linear analysis; however, the CSM suggests that IPs interacts to form an illness schema [4]. Cluster analysis is a technique that considers the associations between patients' IPs, and it has been applied to other disease populations to define profiles of patients based on their IPs [5,6].

Illness perceptions have been found to be associated with several health outcomes in chronic diseases such as diabetes [7], rheumatoid arthritis [8] and breast cancer [6]. Few qualitative studies have explored the perceptions of COPD patients, especially regarding how patients understand, appraise and respond to acute exacerbations [9] and their participation and drop-out in pulmonary rehabilitation [10]. Although information retrieved using qualitative methods enables the collection of rich data there is a lack of evidence related to statistical analyses. IPs have been shown to be linearly associated with HRQoL [11], hospitalization, functioning, depression and anxiety [12]. Harrison et al. found three clusters in a population of patients following hospitalization for an acute exacerbation of COPD labelled 'in control', 'disengaged' and 'distressed'. These clusters significantly differed in the emotional response to the disease, and a between-cluster difference was identified in dyspnea, HRQoL and self-efficacy [5]. Therefore, IPs appear to be associated with several health

outcomes in COPD patients. Despite the relevance of these studies, they were all performed in developed countries, and only one study [5] evaluated IPs using a cluster analysis in an acute population. Evidence suggests that social and cultural factors play a central role in the formation of IPs in those with chronic diseases [13]. Moreover, individuals with distinct racial/ethnic backgrounds often have their own beliefs and values that influence their IPs [14]. We can hypothesize that IPs may present differently in patients from developing countries including Brazil. Therefore, the findings of this study are important to identify the IPs of these populations never studied before. In addition, the identification of illness schema in clinically stable COPD patients through a cluster analysis and the associations between patients' IPs with clinical and psychosocial outcomes and daily life physical activity (DLPA) have not yet been explored. We hope that these findings will assist with the development of targeted interventions and proper treatment tailored to shape negative IPs and improve these important health outcomes

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Objectives

To identify clusters of COPD patients with distinct IPs and explore between-clusters differences in clinical and psychosocial outcomes.

METHODS

Subjects

Between February 2014 and August 2015, 150 consecutive outpatients with COPD diagnosed according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) [1] were recruited during a regular medical visit to a tertiary university hospital. Patients considered clinically stable (no exacerbations in the last 30 days) were included in the study. Patients who met the following criteria were excluded: use of continuous oxygen therapy, musculoskeletal or other chronic lung diseases, cognitive impairment and current participation in an exercise programme.

Ethics: The Hospital Ethics Committee of the hospital approved the study (protocol 569.249), and all patients signed an informed consent form.

Study design

In this cross-sectional study, patients were requested to visit the hospital on 2 non-consecutive days (7 days apart). During the first visit, patients' clinical history, IPs, social support, self-efficacy and lung function were assessed. Afterwards, patients were instructed to wear an accelerometer set to quantify their DLPA for six days. During the second visit, patients were instructed to

return the accelerometer, and the HRQoL, dyspnea and COPD clinical control were assessed.

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Outcomes

Sociodemographic characteristics: Data on age, gender, educational level, marital, socioeconomic and smoking status were obtained from patients' medical records.

Lung function: Lung function was evaluated according to ATS/ERS guidelines [15].

Dyspnea: Dyspnea was assessed with the modified Medical Research Council (mMRC). Higher scores indicate greater impairment [16].

Illness Perceptions: Illness perceptions were evaluated using the Illness Perception Questionnaire-Revised (IPQ-R), which has 9 domains [17]. In 5 of the domains, higher scores indicate more negative IPs: identity (illness label and knowledge of its symptoms), chronic and cyclical timelines (duration of the disease and fluctuation of symptoms), consequences (the effects and outcomes of the illness) and emotional representation (experienced distress). In contrast

in 3 domains, higher scores indicate more positive IPs: personal and treatment control (feelings of control about disease management and beliefs in treatment efficacy) and coherence (how patients' perceive and comprehend the disease). The causal domain was not included because it is a binary variable and therefore did not contribute to the cluster analysis.

Social support: Social support was assessed using the Medical Outcomes Study Social Support Survey (MOS-SSS). Higher scores indicate stronger social support [18].

Self-efficacy: Self-efficacy was assessed using the General Self-Efficacy Scale (GSE). Higher scores indicate stronger self-efficacy [19].

Health-related quality of life (HRQoL): HRQoL was assessed using the Chronic Respiratory Disease Questionnaire (CRQ). The CRQ evaluate four dimensions: dyspnea, fatigue, emotional function and mastery. Higher scores indicate better health status [20].

Clinical Control: Clinical control was measured with the Clinical COPD Questionnaire (CCQ). The CCQ evaluate three domains: symptoms, functional and mental states. Higher scores represent poorer clinical control [21].

Daily Life Physical Activity (DLPA): DLPA (number of steps per day) was measured with a triaxial accelerometer ActiGraph model GT3X+ (Health One Technology, Fort Walton Beach, FL), which has been shown to be an accurate instrument for evaluating DLPA in COPD patients [22]. The device was worn around the waist at the lower back, and patients were instructed to wear it all day for 6 days, except while sleeping and showering. GT3X+ devices do not present a digital display; therefore, they did not provide real-time feedback to patients. Individuals who had at least 4 valid days of data (used the device for at least 8 hours a day) were included in the analysis.

Statistical analysis

Cluster analysis: A cluster analysis was used to classify cases into groups generated by IPs measured with the IPQ-R. Eight domains of the IPQ-R were included and standardized into z-scores. A two-step approach was then applied to the cluster analysis. This type of approach enables the identification of clusters without the clusters being subjected to researcher interpretation [23]. In

the first step, a hierarchical cluster analysis applying Ward's method (with squared Euclidean distance similarity measures) was used to identify the number of clusters and cluster centroids. Afterwards, a K-means cluster analysis was used to cluster cases to centroids. To test for the stability of clusters, K-means clustering was repeated on a random sample containing 50% of the cases.

Between-cluster differences: Differences between clusters were investigated for IPs, demographics, symptoms, self-efficacy, HRQoL and DLPA. T-tests for parametric variables, the Mann-Whitney U test for non-parametric variables and a chi-square test for proportions were applied. A *P* value <0.05 was considered statistically significant. This method is considered suitable for comparing between-cluster differences and has been used in earlier studies using cluster analyses and IPQ as an outcome [5-7]. Bivariate inter-correlations between IPQ-R domains with each emergent cluster were investigated. The data were analysed using SPSS 18.0 for Windows (SPSS Inc, Chicago, USA).

RESULTS

One hundred fifty consecutive patients were enrolled in this cross-sectional study and completed the assessments. Few outliers were observed on the box plots for emotional representation and personal control domains. However, they

were not consistent for the other IPQ-R domains and, therefore, were not removed, maintaining the sample size. Patients' characteristics are presented in Table 1.

Cluster analysis

Two clusters were identified, in cluster 1 patients perceived a higher number of symptoms associated with their disease, greater consequences and a cyclical timeline. They also displayed less illness coherence and more emotional representations. They were labelled "distressed" (n=95). In cluster 2 (n=55), patients associated fewer symptoms with their disease, perceived less cyclical timelines, had less emotional representations and consequences and high illness coherence and they were labelled "coping" (Table 2). Figure 1 displays a visual representation of the illness schema for each of the two clusters. In the validation exercise comprising a random 50% of the sample, 75% were successfully reclassified into the same cluster confirming the robustness of the analysis [5,6,23]. All patients were included in the cluster if they were selected in the cluster analysis.

Between-cluster differences

Significant differences between clusters were noted in five of the eight IPs domains (identity, consequences, timeline (cyclical), illness coherence and emotional representations; $p<0.001$). There were no differences between clusters in the domains timeline (acute/chronic), treatment and personal control (Table 2).

Patients in the distressed cluster were significantly younger ($p=0.03$) and had lower educational levels ($p=0.002$) than those in the coping cluster. Furthermore, patients in the distressed cluster were significantly more disabled by their breathlessness (mMRC; $p<0.0001$), had worse clinical control for all domains of the CCQ ($p<0.0001$) and had worse HRQoL for all domains of the CRQ ($p<0.0001$) and self-efficacy (GSE; $p<0.0001$) than those in the coping cluster. There were no differences between the groups in disease severity (FEV_1), social support and DLPA (Table 1).

Inter-correlations between IPQ-R domains

Both clusters present a significant association ($p<0.05$) between the IPQ-R domains identity and consequences and consequences and timeline (acute/chronic). In the distressed cluster, a significant association ($p<0.05$) was observed between the IPQ-R domains timeline (acute/chronic) and treatment control, consequences and treatment control, timeline (acute/chronic) and

illness coherence, treatment control and illness coherence. In the coping cluster, a significant association ($p<0.05$) was observed between the IPQ-R domains identity and timeline (acute/chronic), personal control and treatment control, personal control and illness coherence, illness coherence and emotional representations (Table 3).

DISCUSSION

To the best of our knowledge, this is the first study to identify distinct illness schema in clinically stable COPD patients, and it is also the first time that IPs in COPD patients from a developing country are described. The present study identified two distinct clusters. The distressed cluster had more perceived symptoms, more negative consequences of the disease, worse understanding of the disease and higher emotional response to illness than the coping cluster. There were no differences in the airway obstruction (FEV_1) between groups, which corresponds to suggestions that IPs are highly individualised and not necessarily in accordance with medical facts [13]. Furthermore, the distressed cluster was also younger, had lower educational levels and had worse dyspnea, self-efficacy, quality of life and clinical control than the coping cluster. The IPs

profiles of individuals with COPD from Brazil were different from the IPs reported in a European population with COPD patients [24].

It has been shown that COPD patients from developed countries seemed to have a good understanding of their illness and were aware of the chronicity of COPD [25]. However, in our study, patients from the overall group presented lower scores in the coherence (respectively, 16.2±3.4 versus 18±3.6) and timeline acute/chronic domains (respectively, 21.1±3.8 versus 26.6±3.6) and also had a higher emotional response to their disease (respectively, 18±4.5 versus 14.5±4.8) compared to individuals with stable COPD from Europe [24]. . A possible explanation for this may be due to the lower educational levels in developing countries. Thus, these patients with a lower ability to receive, process, and understand basic information about their health may also develop less disease coherence and therefore will not recognise the chronicity of their illness, which can lead to negative emotional responses such as anxiety about an unknown disease that makes little sense to them. COPD patients are recognised to have a higher prevalence of symptoms of anxiety and depression than the healthy population [2]. However, the greater presence of mood disorders in patients from developing countries has not yet been explored. In

cardiac patients, psychosocial factors were associated with IPs, whereas no association was found between disease severity and IPs [13].

Additionally, qualitative research conducted in the UK has shown that patients' appraisals of their symptoms can cause feelings of distress, which are associated with feelings of powerlessness and anxiety [10]. Therefore, these data suggest that IPs are different in patients from developing countries and a possible explanation could be that personal and social factors play a central role in IPs formation in COPD patients and help explain the wide variation in IPs among patients with the same diagnosis.

Harrison and colleagues performed a cluster analyses on IPs assessed in COPD patients after being hospitalized due to an acute exacerbation [5]. They found three distinct clusters representing "distressed", "in control" and "disengaged" illness schemas. Those assigned to the distressed cluster present lower treatment control, higher negative consequences and emotional response to the disease than those characterised as in control. Individuals in the disengaged cluster displayed lower illness coherence and fewer emotional representations than the other two clusters. We found only two clusters in our study; clusters 1 and 2 were very similar to "distressed" and "in control" clusters identified by Harrison et al [5]. However, in our study, personal and treatment

control were high in both clusters; therefore, we labelled cluster 1 “distressed” using the same nomenclature and labelled cluster 2 “coping”. We also found similar differences between clusters in dyspnea, self-efficacy and HRQoL.

We did not observe a “disengaged” group in our study. We believe that this difference in the number of clusters may be due to the chosen population since we studied stable outpatients and Harrison and colleagues [5] evaluate post-exacerbation patients. Another hypothesis is that the socioeconomic and environmental condition of countries like Brazil and UK are so different that it may lead to completely different patterns of illness perceptions.

In our study, patients in the distressed cluster had worse HRQoL and self-efficacy. These patients had poor illness coherence and personal control, and it is known that both are necessary for effective self-management so as expected this cluster presented a worse self-efficacy [26]. These results are supported by previous studies demonstrating that better perceptions in the domains identity, consequences, personal control and emotional representation are linearly associated with better HRQoL in clinically stable COPD patients [11, 12]. In addition, the distressed cluster had worse perceived dyspnea and worse clinical control than the coping cluster. Breathlessness and anxiety are known to be associated [27] and the experience of breathlessness and worse symptoms can

have an important impact on how COPD patients feel about their disease and may lead to disruption of the emotional state. Interestingly, patients from the distressed cluster were younger than those in the coping cluster. Another study has shown that healthy elderly individuals with better health perceptions were older than those with worse health perceptions [28]. We also observed that patients from the distressed cluster presented an inverse association between the treatment control (treatment capacity to control/ cure the disease) and consequences (beliefs about illness severity) domains and between the treatment control and coherence (personal understanding) domains. These results are supported by previous studies [5, 24] and suggest that subject´s from the distressed cluster feel like their disease is serious, medical treatment is not effective, and, therefore, nothing can be done to help them. This is most likely in part because the disease is chronic, and they do not understand it. Emotional representations surprisingly do not correlate with the other domains, showing how challenging and complex it is for us to understand why these patients have such strong emotional responses. In contrast, in the coping cluster, the positive association between coherence and personal control domains suggests that patients appear to have a more intrinsic mode of coping – they are not concerned about treatment. They understand their disease and

1 therefore feel in control, despite acknowledging that it is chronic and has severe
2 consequences, as shown in Harrison's "in control" cluster [5].
3 Our findings highlight the variation that exists in the IPs of even clinically stable
4 COPD patients and the impact of the association between their disease
5 perception and several health outcomes. These results have practical
6 implications for the care management of COPD patients because the
7 identification of patients' disease perceptions can be used to target treatment
8 towards those with negative IPs and tailor treatment to improve their IPs profile
9 through several theory-based interventions such as Cognitive Behavioural
10 Therapy and Mindfulness [29-30].
11
12 **Limitations**
13 The use of a cross-sectional design does not allow us to establish a cause-
14 effect relationship between IPs and health outcomes; however, these results
15 may provide direction for future longitudinal studies to evaluate a causal effect
16 in more detail. Although a cluster analysis seems to provide a probabilistic (not
17 logical) analysis, its main advantage is that it considers the relationship between
18 multiple variables in accordance with the recommendations of the CSM.
19 Another possible limitation is that the use of an accelerometer for 6 days could
20 encourage patients to improve their DLPA. To minimize this effect, the

accelerometer used in this study did not provide real-time feedback to the patients.

Conclusion

The present study revealed two meaningful cluster groups of clinically stable COPD patients from a developing country: distressed and coping. We demonstrate that IPs are associated with reduced self-efficacy, clinical control and quality of life. These results emphasize the need to routinely evaluate IPs in COPD patients to target and tailor the proper treatment to improve these important health outcomes.

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Declaration of conflicting interests

The Author(s) declare(s) that there is no conflict of interest.

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