Influence of demographic and disease related factors on the degree of distress associated with symptoms and restrictions on daily living due to asthma in six countries

F.H. Quirk, C.M. Baveystock, R. Wilson, P.W. Jones

ABSTRACT: To investigate the influence of demographic and physiological variables on the degree of distress associated with asthma, 124 patients were recruited from six countries. All patients responded to 76 items relating to symptoms and impacts of asthma on daily living by marking a 10 cm visual analogue scale (VAS) to indicate the degree of distress associated with any particular item. The influence of three factors, age, sex and forced expiratory volume in one second (FEV1), on these VAS scores was investigated. Differences between patients accounted for 13.4% of the total variance (sum of squares) in VAS scores. There were no significant effects of sex, age or FEV1 on VAS score (p>0.05 in each case). The separate proportionate contribution of each of these three factors to the total variance in item scores ranged from 0.02% (FEV1) to 0.2% (sex). There were significant differences between the mean VAS scores from the six countries (p<0.01) but these differences contributed to only 3.6% of the total variance in the measured VAS scores. We conclude that demographic and disease related factors account for very little of the differences in the degree of distress that patients attach to the symptoms and effects of asthma. We suggest that it is possible to make meaningful comparisons between countries of the impact of asthma on patients’ lives.

In the context of health care, quality of life is taken to be concerned with patient’s perception of the severity of their disease and it’s effect on their lives. It is unique to each individual. In contrast the measurement of ‘Quality of Life’ is concerned with the calculation of a value or a profile of values that may be taken to represent that patient’s state within the context of a population of patients. The use of such measures usually, therefore, contains the assumption that patients respond to the effects of their disease in broadly similar ways. We have recently demonstrated that, in patients drawn from one asthma clinic in England, differences between patients in the amount of distress that they associate with the symptoms and effects of asthma on their lives were relatively small. In addition we found that demographic and disease related factors had little effect on the way that these affected their lives [1]. To further test for possible influences on the degree to which patients respond to their asthma, we have now extended our investigation to three European countries - Finland, Italy and Holland, the U.S.A. and Thailand.

Methods

Subjects

One hundred and twenty four patients were recruited from asthma clinics in six countries; England (n=20), Holland (n=20), Finland (n=20), Thailand (n=24), Italy (n=20) and U.S.A. (n=20). Initially 40 patients were recruited in England. To allow a balanced distribution of patient numbers from other countries only 20 patients were randomly selected for inclusion in these analyses.
Procedure

Four interviewers took part in the study. All were from our department. Before collecting the data, an agreed standardized procedure was established such that each interviewer used the same method and style of presentation and gave explanations in the same manner. For non-English speaking countries a translated version of the questionnaire was available, the meaning and content of each item in the questionnaire was validated against the original version through careful discussion between the interpreter and the interviewer prior to administration. Details of patient’s age and forced expiratory volume in one second (FEV₁) were noted, except in Thailand, where peak expiratory flow rates (PEFR) were obtained. Patients were introduced to the concept of a visual analogue scale (VAS) by either the interpreter or the interviewer. Patients were then asked to rate a verbally presented range of items concerning respiratory symptoms and the effect of asthma on everyday life. Twenty nine items referred to the severity and frequency of symptoms (SYMPTOMS) e.g. frequency of cough, wheeze, shortness of breath and sputum production. Forty seven items referred to the effects on everyday life (IMPACTS) e.g. restrictions in mobility, household activities, self-care, social contacts and employment. Patients responded to each item by rating the degree of distress they would experience for the situation described in that item. Ratings were made on a 10 cm VAS scale, one for each item. To minimize any “carry over” effect patients were not able to see their previous responses. The end points of the scale were “no distress” and “maximum imaginable distress”. The score for each item was expressed as a percentage of maximum (i.e. as a percentage of 10 cm).

Analysis

The appropriate non-parametric statistics (Spearman’s correlation coefficient or Mann-Whitney’s U-test) were performed on each item to determine the association between the patients’ VAS scores and each of the measured variables: age, sex, spirometry and nationality. To assess the significance of the association, a repeated measures analysis of variance was performed between each item. To minimize any “carry over” effect patients were not able to see their previous responses. The end points of the scale were “no distress” and “maximum imaginable distress”. The score for each item was expressed as a percentage of maximum (i.e. as a percentage of 10 cm).

Results

Patient details

The details of the patients are summarized by country in Table 1. The overall mean age was 43 yrs (range 17–75 yrs) and overall mean FEV₁ (excluding Thailand) was 79% (range 20–134%). In Thailand the mean PEFR was 87% (range 40–145%). The sex ratio for the total sample was 80/44 (f/m). There was a significant difference in FEV₁ between the sexes; the mean male FEV₁ was 68% compared to 85% for the mean female FEV₁ (ANOVA, p<0.001). There was no difference in age between the sexes (p=0.315). Simple regression analysis was performed between patient’s age and FEV₁ for the total sample and within each country. There were two significant negative associations produced from the within-countries regressions, Holland (r²=0.2, p=0.04) and Italy (r²=0.4, p=0.004). For the total sample (excluding Thailand) there was a significant negative relationship between age and FEV₁ (r²=0.12, p=0.0006).

Table 1. — Summary of the proportionate contribution to the total sum of squares in VAS score (expressed as a percentage) within each country for four factors: between-subject differences, sex, age and FEV₁ (PEFR in Thailand)

<table>
<thead>
<tr>
<th>Country</th>
<th>Between-subjects</th>
<th>Between-sex</th>
<th>Age</th>
<th>FEV₁ or PEFR</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>14.4***</td>
<td>6.8***</td>
<td>1.0***</td>
<td>0.7***</td>
</tr>
<tr>
<td>Holland</td>
<td>5.4***</td>
<td>&lt;0.1 NS</td>
<td>0.3*</td>
<td>0.2*</td>
</tr>
<tr>
<td>Finland</td>
<td>7.5***</td>
<td>0.1 NS</td>
<td>0.2 NS</td>
<td>2.1***</td>
</tr>
<tr>
<td>Thailand</td>
<td>12.8***</td>
<td>&lt;0.1 NS</td>
<td>6.0***</td>
<td>1.1***</td>
</tr>
<tr>
<td>Italy</td>
<td>16.6***</td>
<td>0.7***</td>
<td>&lt;0.1 NS</td>
<td>0.2**</td>
</tr>
<tr>
<td>USA</td>
<td>10.2***</td>
<td>0.1 NS</td>
<td>0.1 NS</td>
<td>&lt;0.1 NS</td>
</tr>
</tbody>
</table>

Significance of the p-values is indicated by: ns: p>0.05; *: p<0.05; **: p<0.01; ***: p<0.001. FEV₁: forced expiratory volume in one second; PEFR: peak expiratory flow rate; VAS: visual analogue scale.

Distribution of VAS scores

The distribution of VAS scores for the SYMPTOMS items showed that 46% of the total number of responses fell into the range of scores between 0–60%, while 27% of the responses fell into the highest score range of 90–100%. In contrast, for IMPACTS items, 23% of the responses lay between 0–60% while 49% of the responses fell into the highest score range of 90–100%. There was a significant difference in the distribution of the scores between the SYMPTOMS and IMPACTS items (Chi², p=0.05).
The proportionate contribution of differences between overall significant difference between the sexes (p=0.16). "(cannot for entertainment or recreation) and one at p<0.01 analysis of variance utilizing all 76 items there was no was seen in three
Influence of sex
A significant difference between the sexes at p<0.05, of these four were significant at p<0.01. These were all IMPACTS items ("not in control of my asthma", "have become frail or an invalid", "most important problem that I have" and "cannot go out for entertainment or recreation"). All of the significant correlations were in a negative direction. In a regression of current FEV₁ against the mean score for each item there was no significant association (p=0.75).
Less than 0.01% of the total variance in VAS scores from all six countries was explicable in terms of differences in FEV\(_1\). Analysed by country, there was a significant effect of FEV\(_1\) on VAS score only in Finland (\(r=0.53, p<0.05\)). The proportionate contribution of FEV\(_1\) or PEFR to the total variance in VAS scores for each country ranged from 0.02% in Italy to 2.1% in Finland (table 2).

**Discussion**

The results from this study correspond very closely to a previous investigation involving 40 British asthmatics [1]. The distribution of visual analogue scale (VAS) scores were very similar, in both patient groups there was a significant difference in the distribution of VAS scores between SYMPTOMS and IMPACTS. Within the two sets of items, SYMPTOMS and IMPACTS, the percentage of responses which fell in the highest range of scores (VAS 90-100%) and lowest range of scores (VAS 0-60%) differed very little between the two populations. In both the previous and current studies, there were no consistent significant effects of sex or FEV\(_1\) on VAS scores for distress. The statistically significant effect of age and the differences between nations were small and contributed little to the total variance (sum of squares) in distress scores. In the analysis of variance, the significant differences in mean VAS scores from different countries arose from differences between Holland and England and between Finland and Holland. The patients recruited in Holland had the highest mean age (50% were over 60 yrs) and the lowest mean spirometry of the six countries in the study. Interestingly, the Dutch patients demonstrated the smallest differences between subjects (only 5.4%) and very small or no significant effects of age, sex or FEV\(_1\), despite the inclusion of patients with a wide range of age and impaired FEV\(_1\). It is not possible to ascribe the high VAS score in Holland to the patients' ages, because in all the countries (including Holland), the influence of age on distress was very small. Furthermore, in those few items in which an age effect was seen, the direction of the association was in the opposite direction, increasing age being associated with less distress for a given item. Significant negative correlations were found between FEV\(_1\) and distress score in a minority of items, but overall this effect is too small to explain the higher distress scores in Holland. We cannot, therefore, satisfactorily explain the uniformly high scores in the Dutch patients. With Holland removed from the analysis there was no significant difference in VAS scores between countries at \(p<0.05\). PATRICK et al. [2] previously demonstrated considerable agreement in the assessment of health status values on the Sickness Impact Profile (a general health status measure) between two English speaking countries - America and England. Our results would suggest that agreement regarding the quantitative assessment of distress associated with asthma is not just restricted to countries which share a similar common language.

The absence of a major effect of impaired spirometry on distress scores supports observations from previous work. Objective measures of lung function appear to have little association with 'quality of life' scores or even exercise capacity. KING and COTES et al. [3] demonstrated that the predictive power of a negative attitude regarding health was greater than that of FEV\(_1\), in the association between these factors and exercise capacity. A similar observation was made by MORGAN et al. [4] using the 12 min walking test in patients with chronic obstructive airways disease. In a large population of patients with chronic obstructive airflow limitation a very poor association was found between spirometry (FEV\(_1\), forced vital capacity (FVC) and PEFR) and Sickness Impact Profile score - an established measure of general health [5]. While in the same patients, the 6 min walking distance correlated well with the Sickness Impact Profile score.

The results from the current study confirm our earlier observation that the distress associated with SYMPTOMS was on average lower than that associated with IMPACT items. This confirmation in a larger and more heterogeneous population adds weight to our hypothesis that restrictions on daily living due to diseases of airflow limitation cause more distress than the symptoms themselves. While there clearly are differences between patients, none of the demographic or disease related factors that we measured could account for these differences. In a longitudinal follow-up of an American national sample, 'well-being' was more closely related to differences in temperament between subjects than objective circumstances such as age [6]. In Holland, ORMEL [7] concluded from a six year longitudinal study that responses to measures of 'well being' seem to be chiefly dependent on the individual. In patients with asthma, other workers have already identified combinations of attitude and personality characteristics that would seem to enable patients to cope better with chronic disease. KINSMAN et al. [8] identified six attitudinal clusters in the responses of hospitalized asthmatic patients to a scale regarding patient attitudes to chronic respiratory illness and hospitalization. KOBASA et al. [9] postulated an adaptive 'personality set', which enables some individuals to minimize negative life events, such as the symptoms and restrictions associated with a chronic disease. By looking at the relationship between patients' own assessment of their disability using 'quality of life' measures and objective measures of respiratory dysfunction it may be possible to identify those patients who would benefit from greater psychological support to enable them to adopt an appropriate model for adapting to life with a chronic disease.

In conclusion, our findings suggest that it is valid to compare patients' responses to the distress associated with asthma, even though the patient sample may differ quite widely in objective circumstances such as age, sex, nationality and disease state. This allows greater confidence in 'quality of life' measures for the pursuit of patient orientated and patient derived assessments of perceived health. In the long-term, this may allow
clinicians to identify, with reference to objective measures of disease severity, those individuals who are the least able to adapt to the restrictions imposed by a chronic disease.

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References