Assessing health status and quality of life in idiopathic pulmonary fibrosis: which measure should be used?

J. De Vries*, A. Seebregts* and M. Drent†

*Department of Psychology, Tilburg University and
† Dept of Pulmonology, University Hospital Maastricht, The Netherlands

Many studies conducted on the health status and quality of life (QOL) of patients with certain chronic diseases have demonstrated that their disease had an impact on their lives. However, less is known about the QOL and health status of patients suffering from idiopathic pulmonary fibrosis (IPF). In the present study, three focus groups of IPF patients (n=10) were run to identify the aspects of QOL or health status that are relevant to this population and to establish which measure is preferable to assess these aspects. The patients completed and discussed the St. George’s Respiratory Questionnaire (SGRQ) and the World Health Organization Quality of Life assessment instrument (WHOQOL-100). Results indicated that hobbies/leisure activities, mobility, transport, social relationships, working capacity, energy and doing things slower were aspects relevant to IPF patients’ QOL. The WHOQOL-100, with an additional social support questionnaire, appeared to be preferable.

Introduction

During the last 20 years, health status and quality of life (QOL) have been studied for a considerable number of chronic diseases, including respiratory diseases such as asthma (1) and chronic obstructive pulmonary disease (COPD) (2). From these studies, it appeared that physical and psychosocial functioning were affected in asthma and COPD (1,2). Only a few studies regarding health status or quality of life (QOL) in interstitial lung disease (ILD) were found. A number of studies assessing QOL and health status in sarcoidosis, another ILD, have previously been conducted. The health status of sarcoidosis patients appeared to be impaired in the fields of sleep and rest, recreation, alertness behaviour, emotional behaviour and social interaction compared to a control group (3). Looking at QOL, Wirnsberger et al. (4) found that the major problem for sarcoidosis patients appeared to be fatigue. Moreover, patients reported problems with their mobility, activities of daily living, working capacity and recreation compared with healthy controls (4). However, the impact of pulmonary fibrosis and idiopathic pulmonary fibrosis (IPF), together accounting for approximately 45% of all ILD diagnosis, on the patients’ QOL and health status is less well known.

From the literature, focus groups appeared to be a reliable method of gathering this information (e.g. 5,6). A focus group is a type of group interview with the primary goal of generating ideas about a particular issue. The reliance in focus groups is on the interaction between the various participants (5). The dynamic interplay of participants replaces their interaction with the interviewer, leading to a greater emphasis on the participants’ points of view (7). Focus groups were run in order to identify the aspects of QOL or health status that are relevant for IPF patients and to determine which questionnaire was preferred for assessing these aspects.

Methods

SUBJECTS AND STUDY DESIGN

Fourteen IPF patients from three participating hospitals (University Hospital Maastricht, Ignatius Hospital Breda, and Tweesteden Hospital Tilburg, The Netherlands) were contacted by their pulmonary physician. Two patients declined, one patient died before the focus group took place and one patient was too ill to attend. The age of the participants (n=10) ranged from 45–76 years (mean 61±11.6 years). Four of these patients (40%) were men. One female participant received supplementary oxygen 24 h a day (see Table 1). The three focus groups were run by the same investigator and taped with permission from the patients. The sessions were subsequently transcribed. All patients signed an informed consent form.
QUESTIONNAIRES

For health status, a disease-specific COPD questionnaire was chosen in order to establish whether this measure was also sensitive for IPF. Of the two most commonly used disease-specific (COPD) health status measures, the Chronic Respiratory Questionnaire (CRQ) (8) and the St. George’s Respiratory Questionnaire (SGRQ) (9), the SGRQ was chosen for this study because it is, unlike the CRQ, a self-report questionnaire. For the assessment of QOL, only a few questionnaires exist. Of these instruments, the only disease-specific measure has been developed for use in psychiatric patients. Thus, a generic measure, the World Health Organization Quality of Life assessment instrument-100 (WHOQOL-100) (10) was used. This questionnaire is a self-report measure which assesses a broad range of aspects. In addition, the WHOQOL-100 appeared to be adequate for sarcoidosis (4,11).

Several weeks before the focus groups took place, participants received two questionnaires by mail. The SGRQ is a self-report health status questionnaire that was translated into Dutch using a forward–backward translation method. The Dutch SGRQ has demonstrated an adequate inter-rater reliability, reproducibility and the ability to quantify change over time (12,13). It has been used in previous Dutch studies (e.g. 14). The SGRQ assesses three components: Symptoms, Activity and Impact. In addition, a total score can be calculated. Scores can range from 0 (no impairment) to 100. In asthma and COPD this measure appeared to be reliable and valid (e.g. 9,12,14).

The WHOQOL-100 (Dutch version, 15) is a cross-culturally developed generic multidimensional QOL measure that has been simultaneously developed in 15 centres around the world, including the Netherlands (6). It consists of 100 items assessing 24 facets of QOL within six domains (Physical health, Psychological health, Level of independence, Social relationships, Environment and Spirituality/religion/personal beliefs) and a general evaluative facet (Overall quality of life and general health) (16). Scores on each facet and domain can range from 4 to 20. The reliability and validity of the instrument, which have also been tested in sarcoidosis, are good (4,11,17). In addition to the 100 items, a set of importance questions pertaining to the WHOQOL-100, which are optional, ask respondents about the importance of the facets within the WHOQOL-100. In the present study and approximately 2 weeks before a focus group took place, the participants completed the questionnaires.

Results

The focus group participants, the majority of whom were women (60%), ranged in age from 45–76 years. None of the patients smoked. Concerning the medical characteristics of the patients, it appeared that most had a slightly decreased forced expiratory volume in 1 sec (FEV1) and a moderately decreased transfer factor of the lung for CO (TL. CO). In addition, six patients were using corticosteroids at the time the focus groups were run (see Table 1).

Patients were asked about their present QOL. A number of aspects were mentioned in all three focus groups: problems with mobility; transport; hobbies/leisure activities; social relations; decline in working capacity; smoking by others; decrease in energy; doing things at one’s own pace. In general, patients said that their lives were centred around their IPF, as they constantly had to be aware of this disease. All their activities needed to be paced. In one group this was related to remaining independent as long as possible. Many activities appeared impossible because of limitations due to IPF. They were not able to perform outdoor activities and hobbies such as swimming, playing bridge at a club, travelling, visiting a theatre and to continue working. The social aspect of these activities appeared to be quite important for the patients. However, passive smoking, problems with mobility and transport as well as being dependent on oxygen and symptoms such as coughing, forced them to seek other hobbies. Although all focus group participants searched for hobbies that could be done at home, social isolation was mentioned as a serious problem. At times, participants had to ‘cross their boundaries’ as some things had to be done. Household activities, e.g. cleaning up after visitors have left, were mentioned as examples. Consequently, the patients’ working capacity was impaired. Whilst they were aware that overactivity could result in shortness of breath and fatigue, patients occasionally chose to prioritize their wants over the risks involved. However, the patients viewed their dyspnoea as something they could control. When they listened to their bodies, paced their activities or remained inactive, they did not experience shortness of breath. Fatigue was mentioned as a serious problem. Another problem was bending forward, which causes dyspnoea. Social relationships deteriorated in quantity and quality (not only in relation to hobbies). Patients attributed this to (i) passive smoking and (ii) their problems in the areas of mobility and transport. When walking became problematic and/or patients could no longer cycle or drive, they were unable to visit friends and acquaintances. This led to a decline in social contacts. Family was important as it provided

<table>
<thead>
<tr>
<th>Table 1. Characteristics of the focus group participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic characteristics</td>
</tr>
<tr>
<td>Age (years)*</td>
</tr>
<tr>
<td>Sex: male/female</td>
</tr>
<tr>
<td>Smoker (yes/no)</td>
</tr>
<tr>
<td>Medical characteristics</td>
</tr>
<tr>
<td>FEV1 (% predicted)</td>
</tr>
<tr>
<td>TL.CO (% predicted)</td>
</tr>
<tr>
<td>PO2 at rest (kPa)</td>
</tr>
<tr>
<td>PCO2 after exertion (kPa)</td>
</tr>
<tr>
<td>Using corticosteroids (yes/no)</td>
</tr>
<tr>
<td>*Data are expressed as mean ± sd. FEV1: forced expiratory volume in 1 sec; TL.CO: transfer factor of the lung for carbon monoxide; PO2: arterial oxygen tension.</td>
</tr>
</tbody>
</table>
practical support and understanding for the patient. Understanding on the part of others declined as they no longer regarded the patient as being very ill. Finally, for the participants under the retirement age of 65 years, being unable to work was a problem. This usually led to less social contact and a decline in income.

Subsequently, the questionnaires were discussed and the patients’ opinion was sought. With regard to the SGRQ, patients did not recognize themselves in the word ‘attack’ that is used in the questionnaire. In one group, patients explicitly pointed out that dyspnoea is dependent on their activities and staying within their own limits. When they control and/or limit their actions, there is no problem. Comments on Section 2 of the SGRQ (activities that usually cause breathlessness) demonstrated that the answer depends on the speed at which activities are carried out. In addition, as a response to some of the statements patients wanted to answer ‘sometimes’: however, this is not a response category. Some activities were not carried out at all because breathlessness was anticipated. Working (in Section 1) was not applicable to patients in a number of cases because the onset of IPF occurred after retirement. However, the response categories for the ‘Work’ question did not include ‘not applicable’. The question concerning medication (Section 5) did not include the option oxygen. Finally, ‘cough’ is not a good word in connection with IPF. The patients said they did not really cough but had hacking cough.

With regard to the WHOQOL-100 the elderly patients indicated that sex was not an issue, thus the facet Sexual activity was not applicable to them. Furthermore, they wanted more questions regarding social relationships than appeared in the domain Social relationships. Participants had no problems in understanding the questions.

In order to provide some information about the health status and QOL of IPF patients, the average scores of the focus group participants are presented in Table 2. Healthy people score approximately 0 on the SGRQ and between 14 and 18 on the WHOQOL-100, in general. For the three reversed facets (Pain and discomfort, Negative feelings, and Dependence on medication or treatment) healthy people score approximately between 6 and 10.

The scores on the importance questions of the WHOQOL-100 indicate that the facets were all viewed as important to their QOL. Using frequency distributions, it emerged that for three focus group participants the facets Bodily image and appearance and Sexual activity were not important (n=2) or only slightly important (n=1).

Discussion

The aspects of QOL that were mentioned by all IPF patients were hobbies/leisure activities, mobility, transport, social relationships, working capacity, energy and a slow pace of life. The practical importance of QOL research in patients suffering from a certain disorder such as IPF is to try to identify the needs and specific (health-related) problems of patients with the aim of improving patient care. Until now, QOL and health status have not yet been studied in IPF patients. In a number of studies in which IPF patients participated, statements concerning an improved QOL were made while QOL was not measured (18–22). In addition, the general statements made in these studies did not indicate which specific aspects of QOL might have improved. In a study by Congleton and Muer (23), QOL was assessed using the activity section of the St. George’s Respiratory Questionnaire (SGRQ). However, this disease-specific questionnaire developed for CNSLD measures health status instead of QOL. Moreover, the applicability of the SGRQ to IPF patients was not tested.

The current popularity of the term QOL is due to the fact that it is increasingly recognized as an important outcome measure of medical treatment and as a supplement to traditional biological end-points such as mortality (24). In the literature, QOL is used as a container concept, i.e. concepts such as functional status and health status are labelled as QOL. Functional status measures physical functioning. Health status assesses the influence of disease on physical, emotional, and social functioning (25,26), analogous to the definition of health of the World Health Organization (27). In contrast, QOL is a person’s perception of their position in life within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating, in a complex way, the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment (16).

In the last two decades, many questionnaires which have claimed to assess QOL have been developed. An example is the existing disease-specific Chronic Respiratory Questionnaire which Mapel et al. (28) validated for IPF. However, this disease-specific questionnaire is not a QOL measure, but a health status measure. Indeed, most so-called QOL measures are, strictly speaking, health status measures (25). When QOL is studied using functional status or health status measures, one major problem is that lower levels of functioning are equated with lower QOL. This contrasts sharply with empirical findings reflecting high perceived QOL despite of low levels of functioning (29). Furthermore, QOL has a much wider scope than the physical, emotional and social domains. Moreover, QOL encompasses the respondents’ own perception of aspects of their life, while health status questionnaires ask respondents about the presence or frequency of behaviour and feelings.

For several reasons, the SGRQ appeared to be an inadequate measure in IPF. First, the focus group participants made many negative remarks about the SGRQ. In addition, the scales of this questionnaire did not reflect the patients’ views of the important aspects of life. Some aspects that were mentioned are covered by one statement in a scale of the SGRQ, which does not provide sufficient information at scale level. Second, when the average SGRQ scores from Table 2 are compared with scores from severe COPD patients in other studies (14,30), it appears that the IPF patients have a better health status than COPD patients although the TlCO of the IPF patients was more impaired (14). Thus, the results from the SGRQ are confusing considering the fact that IPF usually takes a
*The possible range on the SGRQ is 0–100, with 0 indicating no impairment. The possible range on the WHOQOL-100 is 4–20, with higher scores indicating better QOL.

more severe course and is a more life-threatening disease than COPD. Finally, the SGRQ measures only three aspects: ‘Symptoms’ covers disease aspects and ‘Activity’ and ‘Impact’ assess the influence of disease on the patients’ lives. This provides very limited information with regard to problems that patients may experience. Many problems that may be relevant for patients are not measured.

It has recently been demonstrated that QOL cannot be adequately measured using health status instruments (31). Lung cancer patients (n=108) and patients with chronic respiratory disease (n=92) were asked to define QOL in general and to identify what they considered to be a good QOL for themselves by using short, open-ended questions. In general, the most nominated aspects of QOL were health, enjoyment of life and family life. They perceived a good QOL for themselves as consisting of the components Family life, Health and Social life. Consequently, the authors stated that their study results were challenging and served to remind us that the term QOL is misused in many studies as health status measures do not encompass the wider aspects of QOL mentioned by their respondents.

In the developmental phase of the WHOQOL-100, focus groups consisting of patients with a wide variety of diseases were run. This resulted in a questionnaire that measures a broad range of QOL facets, including the aspects mentioned by the patients in the Montezari et al. study (31). From this point of view, it is not surprising that the WHOQOL-100 also incorporates the aspects mentioned by the IPF patients.
The domain Social relationships, particularly the facet of social support, needs to be expanded for use in IPF. This can be achieved by using questions about the patients' evaluation of several kinds of support (emotional, practical, informational) and different people (e.g., partner, children, friends). At present, no measure exists which asks all of these questions. The questionnaire that comes closest is the Social Support Questionnaire (SSQ) (32). However, our experience in other studies has shown that the SSQ repeatedly appears to be too difficult for respondents to complete. A further questionnaire that seems suitable is the Perceived Social Support Scale (33). Although this questionnaire is a generic measure, the perception/evaluation of the respondents is the central point of view. Therefore, this questionnaire would fit very well in the QOL concept.

IPF patients have a limited life expectancy. In cancer patients, much is known about the impact of a short life expectancy. Although such studies are lacking in IPF, the fact that some IPF patients in the focus groups were shocked by the condition of other, more severe IPF patients seems to indicate that the impact on a patient’s life of obtaining a diagnosis with a high mortality is less pronounced in IPF patients than in cancer patients. Patients seem to view a diagnosis of cancer as much more threatening than IPF. It is possible that the psychological burden is less in IPF patients because they are not fully aware of their life expectancy. Future studies are needed to evaluate this hypothesis.

Based on studies in COPD and the present focus group data, it appears that special attention should be paid to breathlessness and its influence on QOL. Furthermore, because QOL, depression and symptoms were mentioned by the focus group participants all these concepts should be incorporated in to future studies.

In conclusion, the WHOQOL-100 questionnaire appeared to be comprehensive and useful in studying the QOL in patients suffering from IPF. Our patients did not mention any aspect of QOL that was not included in the WHOQOL-100. The results of this study indicate that the development of a disease-specific QOL measure of IPF is unnecessary. The SGRQ appeared to be less adequate for measuring health status in IPF, because it did not assess all the aspects mentioned by the IPF patients. When performing a study on the QOL in IPF, the use of an additional questionnaire on social relationships is recommended.

References


