Quality of life in asthma and COPD: development of a disease-specific questionnaire

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A Research-agenda for Behavioural and Psychosocial Research in Chronic Non-Specific Lung Disease

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Abstract

The demands for medical care in patients with chronic non-specific lung disease (CNSLD) and the prevalence of CNSLD will increase. The need, therefore, for behavioural research on CNSLD will also grow. In order to steer behavioural research in CNSLD, research-programming is of great importance. The Dutch Asthma Foundation, which currently is the major financing body of behavioural research in CNSLD, initiated a study on the most prominent topics and conditions for future research in this field. In March 1991, the results of this study have been published in a book "Dealing with CNSLD - research in asthma and COPD; a social science perspective". This report is a literature survey from 1980 to 1990 of behaviour research on asthma and chronic obstructive pulmonary disease (COPD). In addition, a review of current and just completed psychological and social research projects on CNSLD in the Netherlands is presented. Finally, recommendations are made concerning topics as well as conditions for future research on asthma and COPD. These recommendations will be presented in this article.

Introduction

In the recent publication about chronic non-specific lung disease (CNSLD) by the Steering Committee for Future Health Care the expected developments until the year 2005 are described regarding number of patients, number and severity of exacerbations and complications, quality of life and the claims of CNSLD patients on health care.¹ The report finishes off with several recommendations for health care policy. It is expected that the prevalence of CNSLD and the claims on health care will increase and it is recommended that research into the behavioural aspects gets more attention.
In the guidelines on CNSLD, which are being developed by the Dutch Society for General Practitioners, the GPs are advised to discuss subjects such as therapy compliance, feelings of shame and social isolation with the patient.

In the Netherlands the research activities regarding CNSLD in which doctors and psychologists co-operate are increasing. In a special research programme university departments, such as the departments of lung diseases, paediatrics and general practice, co-operate with behavioural scientists in quality of life research. From a literature study that was done for the report 'Coping with Chronic Non-Specific Lung Disease - research into asthma and COPD: a social science perspective' it appeared that research has been focused on the psychological impacts of the disease over the past ten years. The illness-behaviour (coping) of CNSLD patients and its influence on the course of the illness get a lot of attention.

Dutch researchers in particular have - by means of the questionnaires they developed - shown relationships between coping with asthma on the one hand and the course of the disease on the other hand: adequate behaviour during illness leads to a more favourable outcome.

Therapy compliance forms a special item. From various publications it appears that CNSLD patients are not very consistent in taking medication. Although numerous factors influence the use of medication, it is hardly possible to prove direct relationships between these factors, complicating the tackling of the problem. Nevertheless intervention techniques with a behavioural aspect have been shown to influence therapy compliance positively. These techniques consisted of improving communication between doctor and patient, and the patient's taking notes on the use of medication, peak flow values and other data.

Especially in the United States many new intervention techniques, such as patient information services, patient education and self management programmes were developed in the eighties to influence behaviour positively.
and to show the patient what he could do to get more grip on the illness. These techniques were specifically directed at children between the ages of six and twelve. Only in recent years these same intervention techniques have been applied to adults with asthma. Relatively little attention has been paid to other CNSLD patients. Beside CNSLD patients the health professionals are trained further and more research is going on into their functioning. CNSLD has a serious impact on the everyday life of the patient and those close to him. The functioning of the patient with CNSLD in social relationships, for example, the family, the work and school environment, has hardly been looked into systematically.

It may be expected that behavioural and psychosocial research into CNSLD will develop further, which makes the present demand for steering, planning and assessing this kind of research relevant. We have mainly focused on taking stock of the most important themes for future research in this field by interviewing experts, studying the literature, and formulating conditions for research.

**Methods**

Forty-seven Dutch and 13 foreign medical and behavioural experts in CNSLD care and/or CNSLD issues were asked in interviews or in questionnaires to give their views on relevant themes and on the necessary conditions for optimum results. Subsequently, the recommendations were laid down in a questionnaire and sent to the respondents requesting them to score each recommendation according to the degree of relevance.

Apart from that a literature search was done into themes and conditions for CNSLD research.
Results

Interviews

The experts marked behavioural research into CNSLD as 'important'. The themes, which, according to them, merit priority, are mentioned in Table 2.1. The research agenda consisted of a wide range of subjects. On the one hand social support, social isolation and the problems with partners were mentioned, on the other hand psycho-physiological research and the teaching of inhalation techniques. Research into the problems of CNSLD patients in the school or work environment was also considered important. This was in agreement with the findings in the literature that there has been little research into the specific problems these patients encounter in daily life.

It was considered very important to do research into 'quality of life'. In the health care sector there is an increasing interest in this subject, especially concerning the chronically ill. Few studies have, however, paid attention to quality of life in CNSLD patients.

Research into positive and/or negative factors influencing therapy adherence was considered relevant. Questions about the exact reasons for patients not to follow advice and about the ways doctors could influence this were asked frequently. Analysing the problems concerning medication taking, paying specific attention to the aversion patients have, was already considered an important theme in a former investigation concerning behavioural research into CNSLD. Although a relatively large amount of research has been done into this subject, and effective methods to improve therapy taking have been reported, not all the questions on this subject have been answered unequivocally.

Assessing the needs and problems of CNSLD patients was considered important in the early eighties, but, in contrast to therapy compliance, has not been subject of research in the last decade as far as we know. This is poignant, as such re-
search may give important information about the wishes and needs of the patients themselves, and thus create more insight into the direction behavioural research should take.

<table>
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<tr>
<th>Themes</th>
<th>Description</th>
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<tr>
<td><strong>Quality of life</strong></td>
<td>in patients with COPD and their relatives as well as in children and adults with asthma</td>
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<tr>
<td><strong>Needs assessment</strong></td>
<td>which topics are important in research as well as in patient care according to patients themselves (and to parents of young children with asthma)</td>
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<tr>
<td><strong>Psycho-physiological research</strong></td>
<td>in general, i.e. study of the relationship between psychological and physiological aspects in asthma or COPD patients; as well as more specific study on perception of breathlessness - subjective versus objective indicators</td>
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<td><strong>Social aspects of having asthma or COPD</strong></td>
<td>in general, i.e. the impact of social support upon illness behaviour; social development of children with asthma; and more specific, i.e. social problems of COPD patients and their relatives</td>
</tr>
<tr>
<td><strong>Therapy adherence</strong></td>
<td>in general, i.e. research into positive and/or negative factors influencing therapy adherence, and more specific, i.e. the ways doctors could influence patient adherence</td>
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<tr>
<td><strong>Problems in the school and work environment</strong></td>
<td>insight into the problems which patients experience due to their illness in finishing school successfully, choosing and finding the right jobs and in career development</td>
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On top of the suggestions for future research the interviewed professionals recommended methods for behavioural research into CNSLD and suggested preconditions for optimum care to CNSLD patients. Finally they came up with a number of suggestions to improve the policy on behavioural and psychosocial research.
The suggestions named were:

- Stimulating behavioural and psychosocial research into CNSLD, for example by influencing public attention paid to CNSLD, even amongst behavioural scientist, supporting the co-operation between behavioural scientists and doctors in this field, stimulating the focusing on CNSLD in various policy documents (ranging from the Ministry of Health to the Ministry of Education, The Royal Netherlands Academy of Sciences and the Council of Health Research, etc.), and stimulating education on CNSLD during the training of (future) health professionals.

- Creating possibilities for expanding research projects, for example by showing valuable outcomes that can be put into practice.

- Stimulating research from which the patient profits directly, especially patient-related research compared to basic laboratory research, paying attention to the subjects CNSLD patients think highly important and promoting public attention for CNSLD: 'de-stigmatising' the patient with CNSLD.

**Literature study**

The themes in this research agenda are not the only relevant ones for future research. It appears from the literature study that the following subject also merit attention:

- Appreciation of the CNSLD patient. This proves to be a problem among the public in general as well as among health professionals and scientists, together with the recognition of the disease itself. Research into this, especially into the determinants and the ways to influence these factors, is marked as urgent.

- Research into the psychosocial problems of specific groups of CNSLD patients. Seeing the special problems each form of CNSLD causes, and the various problems in the different age categories it is essential to differentiate
between sub-populations, such as: elderly patients with CNSLD, young children with asthma and their parents, non-native speakers with CNSLD, adolescents and CNSLD patients who do not need expert care.

- The working methods of the health professionals should also be looked into and they should be educated further. They should not only be educated in the medical aspects of the disease, but also in the behavioural aspects of CNSLD: these patients benefit from the combination of good medical care and good information.

Discussion

In this paper priorities have been mentioned concerning research into various aspects of CNSLD. On top of that several conditions have been formulated that may prompt empirical research that takes these priorities into account. Not only patients with CNSLD would benefit from such research; health professionals, CNSLD health care in general and policy makers would profit as well.

Support for better relations between doctors and professionals in behavioural sciences has been mentioned frequently. This support, together with the increasing interest in behavioural research into CNSLD, seems to be promoted further by the recently founded national working group for behavioural research into CNSLD. Clinicians as well as scientists in the field of medicine and behavioural sciences, specialised in CNSLD, have become members of this working group. Its purpose is to stimulate -qualitatively as well as quantitatively- Dutch behavioural research into CNSLD, and to promote the co-operation between scientists working in this field.

It should be mentioned that the funding of behavioural research into CNSLD is almost completely taken care of by the Dutch Asthma Foundation. The contribution of the Dutch Government in this research is negligible. The lack of attention for behavioural research into CNSLD by the behavioural scientists
themselves could be a factor, on the other hand it must be noticed that only little extra attention is paid to CNSLD by the government, in spite of the fact that it concerns a chronic ailment that ranks third on the list of causes of death.

If the statement in the report on CNSLD from the steering committee for Future Health care is true ('in the next 15 years a fundamental breakthrough in the search for the cause(s) of CNSLD and its cure is unlikely') - a statement based on an investigation among about 40 experts in the field of CNSLD - themes such as quality of life, therapy compliance, patient education and the information given to doctors and the general public will become increasingly important and demand more attention from the government and other potential subsidisers of research in this field.

References