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

Maillé, A.R.

Citation for published version (APA):

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Chapter 3

Assessing Quality of Life in Chronic Non-Specific Lung Disease: A Review of Empirical Studies Published between 1980 and 1994

A.R. Maillé¹, A.A. Kaptein¹, J.C.J.M. de Haes², W.Th.A.M. Everaerd³

1. Medical Psychology, Department of Psychiatry, Leiden University Medical Centre
2. Medical Psychology, University of Amsterdam
3. Department of Clinical Psychology, University of Amsterdam

Abstract

Chronic non-specific lung disease (CNSLD), a chronic disease with considerable prevalence and mortality rates, is not only a medical problem, it also has significant psychological and social consequences for the patients concerned. Quality of life research on CNSLD was quite underdeveloped for a long period of time, but has recently become an important topic in research as well as in patient care. In order to get insight into the state of the art of empirical research on quality of life in CNSLD, a review of the literature between 1980 and 1994 on this topic is presented. Special attention is paid to definitions and operationalisations of the quality of life concept as well as to questionnaires used to assess quality of life and the aims of quality of life research. Analysis reveals that quality of life is seldom defined clearly and is operationalised in a variety of ways. Most studies have a descriptive nature or pertain to clinical trials. The negative impact of CNSLD on quality of life is well-documented and shows the importance of incorporating assessment of quality of life in research as well as in patient care. Future research is called for; this should be theory-driven, taking into account recent developments concerning disease-specific measures of quality of life.

Introduction

Chronic non-specific lung disease (CNSLD) encompasses asthma, chronic bronchitis and emphysema. All three illnesses concern chronic ailments of the airways and the patient has, for a shorter or longer time, suffered from shortness of breath. In general, asthmatic patients have breathing problems only occasionally and/or over short periods of time, whereas for patients with chronic bronchitis or emphysema (chronic obstructive pulmonary disease - COPD) breathing difficulties are a more constant problem. These chronic diseases have
a prevalence of 10 to 20%. Despite the introduction of new treatment modalities, CNSLD is responsible for a considerable and rising part of the morbidity and mortality in Western countries.\textsuperscript{3,4,5,6,7} Not only is CNSLD a medical-biological problem, it also affects the perceived psychological and social health of patients. CNSLD may have considerable effects on the daily functioning of the patient, as well as on symptoms such as breathing problems, coughing, allergic reactions and cause fatigue and sleeping difficulties, which arise more or less directly from the disorder.\textsuperscript{8,9,10,11} A variety of psychological problems can result from CNSLD, such as fear, shame, helplessness, dependence and depression.\textsuperscript{12,13,14,15} CNSLD can also have considerable effects on relationships and social contacts; social isolation and loneliness have been cited as extra strains on the family and on the partner.\textsuperscript{16,17} In the areas of oncology and cardiology quality of life has been empirically examined.\textsuperscript{18,19,20} In these areas the importance of quality of life is increasingly recognised when considering treatments in experimental studies and patient care. Quality of life research addressing CNSLD-patients has been rather underdeveloped for quite a long period of time. Recently, however, several research groups have started to study quality of life in CNSLD in more detail, and as a result, several questionnaires assessing quality of life have been developed.

In this paper, we aim at providing a review of empirical research on quality of life in CNSLD-patients. The following research questions are addressed:

1. Which definitions and operationalisations of quality of life have been used in (research in) CNSLD;
2. What kind of questionnaires (generic vs disease-specific) have been used to assess quality of life;
3. What were the aims of quality of life research in CNSLD.
Method

A Medline and PsychLIT CD-ROM search for publications in English, between January 1980 and January 1994, was carried out. The following entries were being used: (asthma or chronic bronchitis or emphysema or chronic obstructive pulmonary disease or chronic airflow limitation or obstructive lung diseases or lung diseases not neoplasm) and (quality of life). All keywords were searched as Mesh Heading and as free text in any field including abstracts. The publications resulting from these CD-ROM searches were supplemented with publications from personal files. Publications were included in this paper if they met the following criteria:

(1) addressing groups of adult CNSLD-patients; (2) clear description of the instruments used to assess quality of life; (3) presenting empirical results on quality of life.

Reviews on the state of the art, guidelines for quality of life research and, as well as editorials and letters, were excluded as well as studies on cost-effectiveness and utility assessment (see Rutten-van Mölken, Doorslaer and Rutten for a review).

The definitions of quality of life provided by the authors of the articles -if any- were extracted from the paper. Data on the operationalisation of the concept of quality of life were categorised using the three dimensions (physical, psychological and social functioning) that should, according to quality of life literature, at least have been mentioned. A category "other" was added for overall measures of quality of life as well as to cover aspects of quality of life that could not be clearly categorised as physical, psychological or social functioning.

The questionnaires used to assess quality of life were categorised as generic or disease-specific questionnaires; a combination of these two types of scales was also possible.
The following aims of quality of life research were distinguished: description of the impact of CNSLD on daily life; evaluation of the effects of a therapy or intervention; prediction: screening or classification of individuals, based on quality of life data; and, investigation of determinants of quality of life.

Results

The searches resulted in 150 publications of which 76 did not meet criteria 2 and/or 3: six were reviews, the other 70 did not actually empirically assess quality of life, or did not provide an explicit description of the measures used. In four publications CNSLD-patients formed only a small subgroup of the population under study; they were excluded from further review.

The selected 70 publications were distinguished into two types of studies: firstly, studies documenting the quality of life of CNSLD-patients and secondly, studies on the validation of existing quality of life-questionnaires as well as on the development of disease-specific quality of life-questionnaires for CNSLD-patients. Forty-six publications, referring to 43 studies, documented the quality of life of CNSLD-patients. These are presented and discussed first.

Twenty-four publications were classified as studies in which the validation of existing quality of life-questionnaires or the development of disease-specific quality of life-questionnaires for CNSLD-patients, was the main topic. These will be presented and discussed in the second part of the results section.

Studies documenting Quality of Life in CNSLD

Definition and operationalisation of quality of life

Quality of life is a somewhat elusive concept; it can be defined, operationalised and measured in various ways, and appears to mean different things to different investigators. Nevertheless it provides a short unifying term to refer to a
collection of qualitative concepts, and has facilitated the recognition and understanding of these concepts in clinical practice and clinical trials. Over the past several years some consensus has emerged between researchers in this field concerning the definition of quality of life in functional/operational terms, as well as the components that make up this overall concept: Quality of Life represents the consequences of a disease for the individual's life, and encompasses the physical, psychological and social functioning of a patient.

Table 3.1 presents summaries of the 43 studies. Where applicable, the overall dimensions of quality of life are specified, according to the descriptions of the authors. These specifications are depicted in the legend.

Explicit 'overall' definitions of the concept of quality of life are seldom mentioned, in general operational definitions are used for quality of life. In six studies some definition in operational terms of quality of life is given [1,5,16,26,37,47]. Five authors present clear definitions in terms of the dimensions that make up the concept of quality of life [21,25,27-29,33,35]. Kaptein et al. as well as Malo et al., refer to definitions presented by Spilker: "The consequences of a disease for the individual's life have been conceptualised in the term 'quality of life', which encompasses the physical, psychological and social functioning of a patient"[21] and "quality of life explores the general well-being assessed in different domains: physical status, psychological impact, and social interactions" [25]. McSweeney et al. [27-29] present a 'working definition of life quality' which encompasses four basic dimensions: a) emotional functioning, including mood changes and other psychiatric symptoms; b) social and/or role functioning, including employment, home management and social and family relationships; c) basic behavioral functioning, including self-care skills and mobility; and d) ability to engage in enjoyable hobbies and recreational pastimes.  

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1 Table 3.1: study numbers
Table 3.1: Studies on quality of life (QoL) in Chronic Non-Specific Lung Disease published between 1980-1994

<table>
<thead>
<tr>
<th>STUDY no., first author, year</th>
<th>PATIENTS</th>
<th>CHARACTERISTICS</th>
<th>PH</th>
<th>PSY</th>
<th>SOC</th>
<th>O</th>
<th>SCALE TYPE²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alonso 1992³⁰</td>
<td>76</td>
<td>COPD, no oxygen, reversibility, males</td>
<td>A3</td>
<td>B1</td>
<td>C2</td>
<td>D6-8</td>
<td>G</td>
</tr>
<tr>
<td>2. Anthonisen 1986³⁰</td>
<td>985</td>
<td>non-hypoxemic, ambulatory COPD</td>
<td>A</td>
<td>B1</td>
<td>BC</td>
<td>D1</td>
<td>G</td>
</tr>
<tr>
<td>3. Boo 1984⁴¹</td>
<td>27</td>
<td>severe chronic bronchial asthma</td>
<td>A,3.4</td>
<td>-</td>
<td>C4-6</td>
<td>D6</td>
<td>?</td>
</tr>
<tr>
<td>4. Cockcroft 1987⁴²</td>
<td>75</td>
<td>chronic respiratory disability</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>-</td>
<td>?</td>
</tr>
<tr>
<td>5. Dardes 1990³³</td>
<td>41</td>
<td>severe COPD, long-term oxygen; COPD, no respiratory failure; other chronic diseases</td>
<td>A1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>G</td>
</tr>
<tr>
<td>6. Daughton 1983³⁴</td>
<td>24</td>
<td>pulmonary outpatients and rehabilitation patients</td>
<td>A7.8</td>
<td>B1</td>
<td>-</td>
<td>D10</td>
<td>DS</td>
</tr>
<tr>
<td>7. Dompeling 1992³⁵</td>
<td>162</td>
<td>asthma or chronic bronchitis, GP; settings</td>
<td>A4.5</td>
<td>B1,9,10</td>
<td>C4-6</td>
<td>D1.4</td>
<td>DS</td>
</tr>
<tr>
<td>8. Elliott 1992³⁶</td>
<td>12</td>
<td>COPD, hypercapnic, nipp⁴⁶ at home during sleep</td>
<td>A3,5,6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>G</td>
</tr>
<tr>
<td>9. Foxman 1986³⁷</td>
<td>469</td>
<td>chronic bronchitis</td>
<td>A2</td>
<td>B6</td>
<td>-</td>
<td>D8.9</td>
<td>G</td>
</tr>
<tr>
<td>10. Gray-Donald 1989³⁸</td>
<td>135</td>
<td>COPD with grade 4 or 5 dyspnea</td>
<td>A1</td>
<td>B12</td>
<td>C6</td>
<td>D1.3</td>
<td>G</td>
</tr>
<tr>
<td>11. Gutiérrez 1988³⁹</td>
<td>5</td>
<td>chronic airflow limitation</td>
<td>A1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>G</td>
</tr>
<tr>
<td>12. Guyatt 1987⁴⁰</td>
<td>31</td>
<td>chronic lung disease</td>
<td>A7.8</td>
<td>B1</td>
<td>-</td>
<td>D1.10</td>
<td>DS</td>
</tr>
<tr>
<td>13. Guyatt 1987⁴¹</td>
<td>19</td>
<td>chronic airflow limitation</td>
<td>A7.8</td>
<td>B1</td>
<td>-</td>
<td>D1.10</td>
<td>DS</td>
</tr>
<tr>
<td>14. Guyatt 1991⁴²</td>
<td>24</td>
<td>chronic airflow limitation</td>
<td>A7.8</td>
<td>B1</td>
<td>-</td>
<td>D1.10</td>
<td>DS</td>
</tr>
<tr>
<td>15. Hansson 1982⁴³</td>
<td>128</td>
<td>chronic lung disease</td>
<td>A4.5</td>
<td>B1,9,10</td>
<td>C4-6</td>
<td>D1.4</td>
<td>DS</td>
</tr>
<tr>
<td>16. Heaton 1983⁴⁴</td>
<td>150</td>
<td>hypoxemic COPD without oxygen</td>
<td>A</td>
<td>B1,4,5</td>
<td>BC</td>
<td>D1</td>
<td>G</td>
</tr>
<tr>
<td>17. Hunter 1989⁴⁵</td>
<td>8</td>
<td>COPD</td>
<td>A</td>
<td>B1</td>
<td>-</td>
<td>-</td>
<td>G</td>
</tr>
<tr>
<td>18. Hyland 1993³⁶</td>
<td>42</td>
<td>asthma</td>
<td>A3.5,6</td>
<td>B2</td>
<td>C4,8</td>
<td>D1,12,13</td>
<td>DS</td>
</tr>
<tr>
<td>19. IPPB SG 1983⁴²</td>
<td>985</td>
<td>ambulatory COPD patients</td>
<td>-</td>
<td>B5</td>
<td>-</td>
<td>D1.3</td>
<td>G</td>
</tr>
<tr>
<td>20. Jones 1989⁴⁶</td>
<td>141</td>
<td>chronic airflow limitation, outpatients</td>
<td>A</td>
<td>B6,7</td>
<td>BC</td>
<td>D1</td>
<td>G</td>
</tr>
<tr>
<td>21. Kaptein 1993⁴⁷</td>
<td>274</td>
<td>CNSLD outpatients</td>
<td>A1</td>
<td>B3,6,7</td>
<td>C2</td>
<td>D6</td>
<td>G,DS</td>
</tr>
<tr>
<td>22. Keller 1986⁵⁰</td>
<td>100</td>
<td>COPD</td>
<td>A</td>
<td>-</td>
<td>BC</td>
<td>D1</td>
<td>G</td>
</tr>
<tr>
<td>23. Leverstein 1991⁴¹</td>
<td>1719</td>
<td>asthma</td>
<td>A1.2,6</td>
<td>B6,7</td>
<td>-</td>
<td>D1,30</td>
<td>G,DS</td>
</tr>
<tr>
<td>24. Mahler 1992⁵²</td>
<td>110</td>
<td>COPD, males</td>
<td>A</td>
<td>B12</td>
<td>C,C3</td>
<td>D2.8</td>
<td>G</td>
</tr>
<tr>
<td>25. Malo 1993⁵³</td>
<td>134</td>
<td>occupational asthma and non-occupational asthma</td>
<td>A2.7</td>
<td>B2</td>
<td>-</td>
<td>D1</td>
<td>DS</td>
</tr>
<tr>
<td>26. McKay 1993⁵⁴</td>
<td>15</td>
<td>COPD</td>
<td>A7.8</td>
<td>B1</td>
<td>-</td>
<td>D10</td>
<td>DS</td>
</tr>
<tr>
<td>27. McSweeney 1980⁵⁵</td>
<td>166</td>
<td>severe COPD</td>
<td>A,A3,4</td>
<td>B1,4,5</td>
<td>BC, C1</td>
<td>D1,5,6</td>
<td>11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY</th>
<th>PATIENTS</th>
<th>DIMENSIONS OF QoL</th>
<th>SCALE TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. McSweeny 1982&lt;sup&gt;11&lt;/sup&gt;</td>
<td>203 73 hypoxemic COPD and healthy controls</td>
<td>A,A3,4, B1.4,5 BC, C1, 4, 5, 7,8 D15,6,11</td>
<td>G</td>
</tr>
<tr>
<td>29. McSweeny 1985&lt;sup&gt;56&lt;/sup&gt;</td>
<td>303 99 severe COPD controls</td>
<td>healthy A,A3,4, B1.4,5 BC, C1, 4, 5, 7,8 D15,6,11</td>
<td>G</td>
</tr>
<tr>
<td>31. Nocon 1991&lt;sup&gt;26&lt;/sup&gt;</td>
<td>18 asthma</td>
<td>A1 B1 C4-6 D12, DS</td>
<td></td>
</tr>
<tr>
<td>32. Prigatano 1984&lt;sup&gt;56&lt;/sup&gt;</td>
<td>985 25 mild hypoxemic COPD and healthy controls</td>
<td>A,A3,4, B1.4, 7-9, 11-12, 14-14 BC, C1, 2.4, 5, 7,8 D1,5,6,8,11</td>
<td>G</td>
</tr>
<tr>
<td>33. Ringsberg 1990&lt;sup&gt;31&lt;/sup&gt;</td>
<td>38 asthma</td>
<td>A1.6 B1.3-8, C1.4-8 D1, G, DS</td>
<td></td>
</tr>
<tr>
<td>34. Ringsberg 1993&lt;sup&gt;52&lt;/sup&gt;</td>
<td>15 asthma and functional breathing disorder</td>
<td>A1.6.7, B4.7, C1.4-8 D6, G, DS</td>
<td></td>
</tr>
<tr>
<td>35. Schrier 1990&lt;sup&gt;63&lt;/sup&gt;</td>
<td>109 CNSLD in GP</td>
<td>A,A1, BC D1, G</td>
<td></td>
</tr>
<tr>
<td>36. Shapiro 1992&lt;sup&gt;54&lt;/sup&gt;</td>
<td>184 severe COPD, 30-75 years of age</td>
<td>A - - D1, G</td>
<td></td>
</tr>
<tr>
<td>37. Ström 1990&lt;sup&gt;45&lt;/sup&gt;</td>
<td>43 hypoxemic COPD, oxygen at home</td>
<td>A,A3,4, B1 BC, C1, 4-5, 7,8 D1,5,6,8,11</td>
<td>G</td>
</tr>
<tr>
<td>38. Toshima 1996&lt;sup&gt;66&lt;/sup&gt;</td>
<td>119 COPD</td>
<td>- B7 - D2, G</td>
<td></td>
</tr>
<tr>
<td>39. Travner 1988&lt;sup&gt;57&lt;/sup&gt;</td>
<td>30 severe COPD</td>
<td>A,A3-4, 7-10 B1.4, 6-9, 12-14 C1.2, 4-8 D1,3, 5-8, 11 G, DS</td>
<td></td>
</tr>
<tr>
<td>40. Vale 1993&lt;sup&gt;68&lt;/sup&gt;</td>
<td>43 COPD asthma / other lung diseases</td>
<td>- - - D1, G</td>
<td></td>
</tr>
<tr>
<td>41. Van Schayck 1991, 1992&lt;sup&gt;55,60&lt;/sup&gt;</td>
<td>223 moderate asthma or COPD, in GP setting</td>
<td>A3 B1.9 C2 D6-8, G</td>
<td></td>
</tr>
<tr>
<td>42. Weir 1993&lt;sup&gt;71&lt;/sup&gt;</td>
<td>105 severe chronic airflow obstruction</td>
<td>A7.8 B1 - D10, DS</td>
<td></td>
</tr>
<tr>
<td>43. Williams 1989&lt;sup&gt;27,72&lt;/sup&gt;</td>
<td>92 chronic obstructive airway disease</td>
<td>A,A3,4 B1.2-6, 7 BC, C1, 4-5, 7,8 D1,5,6,8,11</td>
<td>G</td>
</tr>
</tbody>
</table>

**Legend for Table 3.1: Measured dimensions of QoL**
- **PH**: Physical Functioning: A: overall physical functioning; A1: physical activities, physical capacities, activities of daily living; A2: physical disability, restricted activities, limitation of activities; A3: physical mobility, ambulation, dexterity; A4: self-care, body-care & movement; A5: physical/sensual aspects of marriage; A6: physical symptoms, in general; A7: dyspnoea, shortness of breath; A8: peripheral sensory complaints; A9: anorexia; A10: responses to environmental stimuli and the need to avoid these stimuli. **PSY**: Psychological Functioning: B: overall psychological functioning; B1: psychological/emotional status, emotions; emotional reactions; emotional functioning; emotional behaviour; B2: emotional dysfunctions; emotional distress; B3: psychological well-being, pleasantness; B4: general psychopathology and or psychiatric problems hysteria, paranoia, psychosis, psychoses, schizophrenia, mania, psychopathic derivate; B5: mood changes; B6: anxiety, worry; B7: depression, negativism, hopelessness; B8: tension, irritability, anxiety; B9: dependency on others, helplessness; B10: emotional aspects of marriage; B11: hypochondriasis; B12: mental health, outlook, stability; B13: anger, belligerence, obstreperousness; B14: other: suspiciousness, bizarre, verbal expansiveness, decaenthesia. **SOC**: Social Functioning: C: overall social functioning; C1: social activities, social interactions, C2: social impairment, social isolation, alienation, withdrawal; C3: social role functioning in general; C4: employment, work, income; C5: home management, care of grandchildren; C6: marriage, social and family relationships, social support; C7: communication, C8: hobbies and recreational pastimes/leisure activities. **O/Other**: D1: overall or general QoL, life in general; D2: health perceptions, subjective health, health status, life satisfaction; overall quality of well-being; D3: recent life changes; D4: effects of symptoms and/or of treatments; D5: intellectual functioning, alertness, behaviour, confusion, memory; D6: sleep and rest; D7: energy, activation, vigour, hyperactivity; D8: pain; D9: bed-days; D10: control over the disease; D11: eating; D12: effects on others; D13: medication usage. **Type of scales**: G: generic QoL-questionnaires and/or personality questionnaires; DS: disease-specific QoL questionnaire; **type of questionnaire**: generic vs disease-specific unknown. ***: refers to the psycho-social dimension of the SIP. **GP**: General Practitioner; ***NIPPV**: Nasal Intermittent Positive Pressure Ventilation.
Ringsberg et al. [33] define quality of life as self-assessed leisure activities, social interaction, physical activities and emotional adjustment. And Schrier et al. [35], state that "CNSLD proved to have an extensive impact on patients' physical, psychological, and social functioning, or, in other words, on their quality of life" (p.894). 

Information on the operationalisation of the concept of quality of life in terms of the dimensions of quality of life that were studied, was generally derived from the questionnaires used to assess quality of life, i.e. from their subscale scores and overall scores. It was categorised using the three dimensions (physical, psychological and social functioning) that should, according to quality of life literature, be minimally mentioned. A category "other" was added for measures of overall quality of life. This category was also used to cover aspects of quality of life that could not be clearly categorised as physical, psychological or social functioning.

There is a wide variety in the assessment of quality of life in terms of the inclusion of particular dimensions. About fifty percent of the studies mention at least aspects of the three dimensions of quality of life. Physical functioning is most frequently measured. In some studies conclusions on quality of life are based on physical functioning only [6,11]. The most neglected dimension is 'social functioning'. There is considerable diversity in the measurement of concepts within each dimension: some studies assess 'overall' physical, psychological and /or social functioning, whereas other studies assess these measures as a dimension based on the summation of scores on several subscales (for example, the psychosocial and physical dimension of the Sickness Impact Profile). Another set of studies assesses aspects of these dimensions, for example
dyspnoea and peripheral sensory symptoms (A7, 8)\(^2\) [8,12-14,26,46] in the physical dimension, and anxiety/worry [9], sometimes in combination with depression [20,23], in the psychological dimension.

Concerning the *physical* dimension overall physical functioning (A) is measured most often, as well as physical/general activities (A1), mobility (A3) and disease-specific symptoms such as dyspnoea and shortness of breath (A7). Self-care (A4) and other sensory symptoms (A8) are also measured rather often. The *psychological* dimension is especially measured by overall psychological/emotional status (B1) or in combination with social functioning (BC). General psychopathology (B4), mood (B5) and more specific emotions such as anxiety (B6) and depression (B7) are assessed in many studies. Apart from the overall measurement of *social* functioning (C and BC), especially employment (C4) and home-management (C5) are frequently assessed aspects of the social functioning dimension. Inspection of the "other" category shows that *overall* quality of life (D1) is studied in more than half of the studies. Sleep and rest (D6), intellectual functioning, as well as pain and eating habits are also measured in many instances.

**Type of questionnaires, which have been used to assess quality of life: generic versus disease-specific quality of life-questionnaires.**

Generic quality of life questionnaires address more universal features and consequences of illness. They are 'supposed to be broadly applicable across types and severities of diseases, and designed to summarise a spectrum of the concepts of health related quality of life that apply to many different impairments, illnesses, patients and populations'.\(^7^4\) However, important disease-specific

\(^2\) Table 3.1: measured dimensions of Quality of life
complaints and symptoms may be overlooked when only generic quality of life-questionnaires are used.\textsuperscript{75} Disease-specific quality of life-questionnaires, designed to assess specific diagnostic groups or patient populations, take into account the specific concomitants of the disease. Combinations of generic and disease-specific instruments are used in quality of life-research, combining the advantages of both types of questionnaires.\textsuperscript{76}

In 26 out of the 43 studies, generic questionnaires are used to measure quality of life. These are generic quality of life questionnaires as well as, parts of, questionnaires on psychological or psychiatric problems used to make up a set of instruments to assess (aspects of) quality of life. The Sickness Impact Profile (SIP) \textsuperscript{[2,16,19-22,27-29,32,35,37,47]}, General Health Questionnaire (GHQ) \textsuperscript{[4,47]}, Nottingham Health Profile (NHP)\textsuperscript{[1,7,33,45]}, Katz Adjustment Scale (Katz-R) \textsuperscript{[27-29,32]} and Spitzer’s quality of life-questionnaire \textsuperscript{[10,30,36]} are examples of generic quality of life questionnaires that are often used. The Daily Activities List (DAL)\textsuperscript{[35]}, quality of Well-being Scale (QWB-S)\textsuperscript{[38]}, Karnofsky-scale \textsuperscript{[7]} and MOS-20 \textsuperscript{[24]} are rather seldom used. Questionnaires on psychological of psychiatric problems, in some studies used to assess parts of quality of life are, for example: the Minnesota Multiphasic Personality Inventory (MMPI)\textsuperscript{[16,27-29,32]} and the Profile of Mood States (POMS)\textsuperscript{[2,17,19,27-29,32]}. The generic health-related quality of life questionnaires as well as the questionnaires on psychological or psychiatric problems are in general well tested. Use of these questionnaires facilitates comparison of the quality of life of CNSLD-patients with the impact of other diseases on quality of life.

In 11 studies quality of life is assessed using disease-specific questionnaires only. In general these are well-developed, well-documented questionnaires. The Chronic Respiratory (Disease) Questionnaire (GR(D)Q) is used most frequently \textsuperscript{[8,12-14,26,40,46]}. Other disease-specific quality of life questionnaires used in
these studies are the Asthma Quality of Life Questionnaire (AQLQ)[18] and the Living With Asthma Questionnaire (LWAQ) [25]. These are some of the disease-specific quality of life questionnaires, which have been developed quite recently. They will be discussed in more detail in the second part of the results section.

The combination of generic and disease-specific quality of life questionnaires was used in four studies [21,23,34,38]. Combinations of well-known quality of life questionnaires were used, for example Levenstein [23] used the SIP, the Hospital Anxiety Depression Scale (HAD) and a disease-specific quality of life scale: the St. George's Respiratory Questionnaire ((S)GRQ), or combinations of parts of personality questionnaires and disease-specific scales. In the study of Kaptein et al. [21], for example, the anxiety, depression and sleep-disorder subscales of the Symptom Check List, 90 items (SCL-90) were combined with the List of Daily Activities and the Optimism and Stigma subscales of the Respiratory Illness Opinion Survey (RIOS).

Aims of quality of life research in CNSLD

Generally, the following purposes are distinguished in quality of life research: description of the impact of CNSLD on daily life; evaluation of the effects of a therapy or intervention; and prediction: screening or classification of individuals, based on quality of life data. These different aims place specific demands on the operationalisation of the concept of quality of life as well as on psychometric qualities of the questionnaires. For example, a questionnaire developed for evaluative indices has to be sensitive to change, a requirement not essential when description of the quality of life of a group of patients is the aim of a study. The purposes of the incorporated studies are presented in Table 3.2.
By giving a description of the impact of a disease on patients' daily life by using quality of life-data we can get information on the reactions of patients to their disease and, eventually, their treatment. This may give more theoretical insight into the effects of (chronic) diseases and their treatment on patients.

Table 3.2 Aims of Quality of Life Research in CNSLD

<table>
<thead>
<tr>
<th>Aim of the study</th>
<th>Study numbers (see Table 3.1)</th>
<th>Number of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>1, 5, 9, 15, 21, 25, 27-29, 31, 34, 35, 43</td>
<td>13</td>
</tr>
<tr>
<td>Evaluation</td>
<td>2-4, 8, 11-14, 16, 17, 19, 23, 26, 33, 36-38, 40-42</td>
<td>20</td>
</tr>
<tr>
<td>Prediction</td>
<td>7, 18, 39</td>
<td>3</td>
</tr>
<tr>
<td>Determinants of QoL</td>
<td>6, 10, 20, 22, 24, 30, 32</td>
<td>7</td>
</tr>
</tbody>
</table>

On the other hand, the results of this kind of quality of life research may also enhance our understanding of patients’ problems and needs, and lead to organising specific forms of care.

Almost 25 percent of the studies [13 out of 43] on quality of life in CNSLD are carried out with description of the quality of life of CNSLD-patients as their major aim. In most of these studies relationships between quality of life and some other (anamnestic and/or demographic) variables are also studied. These studies show that, in general, CNSLD-patients experience impaired quality of life in many aspects of daily life. McSweeney et al. [27-29], one of the first groups of researchers who studied quality of life in CNSLD-patients, found that patients with severe COPD experience major emotional disturbances, including depression, somatic preoccupation and general dissatisfaction with life. Using the SIP, they concluded that COPD has a significant negative impact on sleep and rest, home-management activities, employment and recreational activities. Neuropsychological impairment was positively related to restrictions in activities of daily living as well as to problems with basic social role performance.
The significant impact on quality of life of COPD was also demonstrated by Alonso et al. [1], Dardes et al. [5], Schrier et al. [35] and Williams & Bury [47]. Foxman et al. [9] studied the effects of chronic bronchitis on daily functioning and concluded that worry, pain and restricted-activity-days were the most commonly reported impact, regardless of age, sex or smoking habits. Ringsberg et al. [34] compared personality, psychosocial and somatic parameters of asthma patients with those of patients suffering from Functional Breathing Disorder (FBD). FBD is a condition with asthma-like symptoms, but without the physiological signs of asthma. It was found that FBD-patients had a lower quality of life than asthmatic patients. Nocon & Booth [31] assessed the quality of life of asthmatic patients. They concluded that all people interviewed had experienced some impact of the disease on their lives, although in varying degrees. People were affected in different ways: employment, schooling, physical activities, social interaction, personal relationships and emotional well-being. The overall social impact was positively correlated with the subjective severity of asthma (measured by a grading-scale based on descriptions provided by the patients themselves).

Secondly, data on quality of life can also be used to evaluate the effects of a therapy or intervention, and to compare different groups of patients or patients compared to 'normals'. In this way it may be possible to steer treatment or enhance quality of care. Somewhat less than half the studies (20 of 43) are evaluative, and assess the effects of treatments or interventions on quality of life. Part of them evaluate the effects of medication [3,13,14,23,26,45,46], and quality of life is one of the outcome measures. In the study of Levenstein [23] 1719 asthmatic patients participated in a double blind comparative efficacy and safety study of nedocromil sodium versus placebo. With regard to quality of life, measured with the disease-specific (S)GRQ, a statistically significant improvement was shown in the nedocromil group. This improvement was also
found using generic quality of life questionnaires (the SIP and HAD), although it was not statistically significant. Van Schayck et al. [45], however, found no effects on quality of life, assessed with the NHP, when studying the effects of bronchodilator treatment (continuous versus symptomatic) on CNSLD-patients in general practice with serious impairments in quality of life. Other studies evaluated the effects of several ventilation therapies on severe COPD-patients [8,11,16,19,36,37]. Except for Gutiérrez et al. [11], who found an improvement of quality of life using the Karnofsky scale, all other studies concluded that the type of therapy has no effect on quality of life.

In a prospective study, with a 3-year follow up, the standard treatment was evaluated, in order to identify factors influencing death and lung function [19]. The remaining studies evaluated some kind of rehabilitation or education programme [4,12,17,33,38,40], most of which appear to have a positive effect on quality of life. Ringsberg et al. [33], for example, evaluated the effect of education of adult asthmatic patients at a special asthma school with regard to knowledge of disease, treatment and quality of life. They found that although knowledge improved in the experimental as well as in the control group, only the experimental group showed improved quality of life as well as a reduction in the number of hospitalisations.

A third possible objective of evaluating quality of life is *prediction*: assessing quality of life is used to screen or classify individuals, for example, taking quality of life data into account in order to predict how long a patient will live. In three studies quality of life data were used as predictive variables: Traver [39] used measures of symptoms and quality of life to predict emergent use of institutional health care resources in people with COPD. Quality of life was assessed using the SIP and Katz-R. More symptoms and impairment of quality of life were found in the high emergent group. Discriminant analyses provided 80% correct prediction
by (in descending order of importance): peripheral sensory symptoms (a subscale of the Bronchitis Emphysema Symptom Checklist (BESC))\(^8^3\), emotional behaviour (SIP dimension), and alienation (BESC-subscale). Dompeling et al. [7] found lung function indices and also quality of life (energy and pain from the NHP) and packyears to be significant predictors of fast progression of the disease in patients with chronic bronchitis in general practice. In a study on steroid prescribing for asthmatics [18] it was found that physician's prescription decisions were mainly based on patients' psychological reactions during attacks (panic-fear and irritability). Although disease-specific quality of life between attacks correlated with prescription behaviour, it did not explain additional variance in this variable.

A fourth aim of quality of life research relates to the investigation of *determinants of quality of life*. This kind of research may help to build and test theories about quality of life the way it is influenced by other variables. A considerable number of the studies aimed at finding out the determinants of quality of life of CNSLD-patients. It has already been mentioned that there is some overlap with studies with a more descriptive character; in most of these papers also relationships with demographic and/or anamnestic variables are investigated, although not as the main objective. There are however seven studies that investigated the determinants of quality of life in a more explicit way [6,10,20,22,24,30,32]. Prigatano et al. [32] studied quality of life and its predictors in patients with mild hypoxemia and COPD. They concluded that this group of patients was less impaired in physical functioning compared with previous studies on COPD patients with hypoxemia, but about equally impaired in psychosocial functioning and dysphoric mood. The degree of self-reported tension-anxiety (POMS-subscale) was the single greatest explainer of both physical and psychosocial measures of quality of life. The level of exercise completed, FEV\(_1\), and
neuropsychological status were significant related to physical limitations but not to psychosocial functioning. Gray-Donald et al. [10] studied the possible influence of the nutritional status of severe COPD-patients on functional capacity, including quality of life. No difference in quality of life-scores (Spitzer's-index) was shown among the three different weight groups of COPD-patients.

The relationships between general health (measured with the SIP) and respiratory symptoms, physiologic measures and mood in patients with chronic airflow limitation was investigated by Jones et al. [20]. It was shown that walking distance correlated with the SIP better than any spirometric measure or arterial saturation and accounted for 41% of the variance in quality of life, measured with the SIP. Together with depression and dyspnoea, walking distance accounted for 62% of total SIP-variance. Age, sex and response to bronchodilator were not correlated with the SIP-score. Lack of influence of spirometric measures on quality of life was also found by Keller [22] and Mahler et al. [24]. Daughton et al. [6], however, did find a relationship between lung function (FEV₁) and quality of life. However, it has to be mentioned that quality of life was measured by a questionnaire assessing physical capacity only. Moody et al. [30] examined the interrelationships among variables significantly associated with chronic bronchitis in COPD and the relative influences of these variables on functional status and quality of life. It was found that dyspnoea severity had a sizeable effect on functional status and quality of life. Disease severity was more strongly correlated to functional status ("depression and mastery") than to quality of life (measured with the Spitzer's quality of life-questionnaire). They also found personality characteristics (neuroticism, anxiety) to be negatively related to quality of life.
Studies on the validation of generic quality of life questionnaires and the development of disease-specific quality of life questionnaires for CNSLD-patients

Twenty-four articles resulting from the literature search were classified as papers on the validation, sometimes after adaptation, of generic quality of life-questionnaires for CNSLD-patients, or as publications on the development of new quality of life-questionnaires for CNSLD-patients.

Validation of generic quality of life questionnaires in CNSLD-patients. Four articles presented data on the validation of existing questionnaires, sometimes after adaptation, in (sub)groups of CNSLD-patients:

The Additive Activities Profile Test (ADAPT-QoL-scale)\(^{84}\) was validated against functional work capacity in patients participating a pulmonary rehabilitation programme. This scale is described as a generic quality of life-questionnaire with possible uses for description and evaluation. It addresses physical functioning only.

The Medico Psychological Questionnaire for Lung Patients (MPQL),\(^{85}\) an adapted version of the Medico Psychological Questionnaire for Heart Patients (MPQH),\(^{86}\) was used to examine the changes in psychological parameters before and after pulmonary rehabilitation in COPD-patients. This scale contains four sub-scales: well-being, experienced invalidity, displeasure and social inhibition. Reliability and validity of this scale were demonstrated. Apart from the social inhibition scale, which did not show the expected correlations with other variables, this questionnaire can be useful to determine psychological aspects and consequences of the disease in COPD-patients.

The Quality of Well-being Scale (QWB) was validated as an outcome measure in COPD by Kaplan and co-workers.\(^{87,88}\) This scale, originally designed for use as a
generic health outcome measure, involves three dimensions of functioning: mobility, physical activity and social activity. It provides a point-in-time expression of well-being, ranging from 'zero' for death to 'one' for optimum functioning. In these studies it is shown that the QWB-scale correlates with performance and physiological measures in COPD-patients and might be useful as an outcome measure, for example, in rehabilitation research.

The *Satisfaction with Illness Scale*, a measure of positive health related quality of life, was developed by Hyland & Kenyon. They state that measurement of quality of life often takes the form of questions about the *problems* associated with the illness. Hyland has proposed a model of health-related quality of life constructs, including a construct of positive evaluations of health. The Satisfaction with Illness Scale was developed to measure these positive consequences of illness. Its reliability and validity have been tested and demonstrated in a population of chronic bronchitis patients.

*The development of disease-specific quality of life questionnaires.* Recently several research groups have started to study quality of life in CNSLD in more detail, and as a result several disease-specific questionnaires assessing quality of life have been developed. These questionnaires are presented in Table 3.3 arranged according to the patient group they are meant for, number of items, type of scores and the dimensions they are made up of. Next we will review the presented disease-specific quality of life questionnaires on the basis of our research questions: the way in which quality of life is defined, the dimensions of quality of life that can be assessed with each scale and the aim for which the questionnaire is developed.
### Table 3.3  Disease-specific quality of life (QoL) questionnaires for patients with Chronic Non-specific Lung Disease

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Patient group</th>
<th>Items (n)</th>
<th>Type of scores</th>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Respiratory Respiratory (Disease) Questionnaire CR(D)Q [8,9]</td>
<td>Chronic Airflow Limitation</td>
<td>20</td>
<td>four subscale scores one overall score</td>
<td>Physical: dyspnoea, Psychological: emotional function Social: - Other: mastery, fatigue</td>
</tr>
<tr>
<td>Living with Asthma Questionnaire LWAQ [34,93]</td>
<td>Asthma</td>
<td>68</td>
<td>one overall QoL-score</td>
<td>Physical: colds, mobility, sex, work and other activities Psychological: dysphoric states and attitudes Social: social/leisure, sport, holidays Other: sleep, effects on others, medication usage</td>
</tr>
<tr>
<td>St. George's Respiratory Questionnaire (S)GRQ [34,95,96]</td>
<td>Asthma and COPD</td>
<td>76</td>
<td>three subscale scores one overall QoL-score</td>
<td>Physical: respiratory symptoms, activities causing/limited by breathlessness Psychological/Social: emotional and social impacts on daily life Other: -</td>
</tr>
<tr>
<td>Asthma Quality of Life Questionnaire AQLQ [97-99]</td>
<td>Asthma</td>
<td>32</td>
<td>four subscale scores one overall QoL-score</td>
<td>Physical: symptoms, activity limitation, exposure to environmental stimuli Psychological: emotional function Social: - Other: -</td>
</tr>
<tr>
<td>(Australian) Asthma Quality of Life Questionnaire A-AQLQ [97]</td>
<td>Asthma</td>
<td>20</td>
<td>four subscale scores one overall QoL-score</td>
<td>Physical: breathlessness &amp; physical restrictions Psychological: mood disturbance Social: social disruption Other: concerns for health</td>
</tr>
<tr>
<td>Life Activities Questionnaire for Adult Asthma LAQAA [100]</td>
<td>Asthma</td>
<td>70</td>
<td>one overall restricted activity score</td>
<td>Physical: physical activities, outdoor activities Psychological: emotions and emotional behaviour forcing restricted activities Social: work activities, home care Other: miscellaneous activities, eating and drinking</td>
</tr>
</tbody>
</table>
The *Chronic Respiratory (Disease) Questionnaire (CR(D)Q)* was the first disease-specific quality of life questionnaire. No explicit overall definition of the concept of quality of life is presented in the publications on the development of this scale. It is stated that the questionnaire has to cover "areas of physical and emotional dysfunction that patients themselves experience and feel are important" and "patients were asked to list all physical, emotional or social problems they had as a result of their chest disease". In an article on the significance of changes in scores on this questionnaire, quality of life is described as "a jargon term (...) to describe health status related to how a person feels, and how she or he functions in daily activity". The questionnaire consists of 20 items, and provides one overall score and four subscale scores in the following *dimensions*: dyspnoea (physical dimension), emotional functioning (psychological dimension), mastery and fatigue (other). Fatigue can also be classified as part of the physical dimension, and mastery (control over the disease) can also be seen as an aspect of psychological functioning. It is designed for use in clinical trials (evaluation) and administered by an interviewer. The dyspnoea scores are individualised, which has the advantage of increased patient relevance and possible increase in sensitivity to change. However, it is difficult to use this questionnaire to define a population or to make comparisons within it. Although the questionnaire was developed for people with respiratory disease in general (including both asthma and COPD), it actually seems biased towards patients with chronic bronchitis and emphysema. Some critics of this scale state that it does not assess the performance of activities (the dyspnoea scale addresses dyspnoea during activities) and that there is no social dimension. The *Living with Asthma Questionnaire (LWAQ)* was designed "to measure the patient’s experiences of asthma" and to be consistent with the *definition* that "quality of life represents the functional effect of an illness and its consequent
therapy upon a patient, as perceived by the patients. Quality of life is perceived as multi-domain in that a particular condition may affect life experiences in a variety of ways. A single overall quality of life-score is obtained based on the summation of the patients responses to 68 items in 11 domains, covering several dimensions of quality of life: colds, mobility, sex, work and other activities (physical dimension), dysphoric states and attitudes (psychological dimension), social/leisure, sport, holidays (social dimension), sleep, effects on others, medication usage (other). There are no subscales reflecting the several dimensions. It is completed by the patient and intended for use in clinical trials, and to assist in individual patient management. It was designed specifically for asthmatic patients, to assess their functioning between asthma attacks.

The St. George's Respiratory Questionnaire ((S)GRQ) is described as an instrument designed "(...) for measuring impaired health and perceived well-being ('quality of life') in airways disease." No further explicit definitions of quality of life are presented. In a publication on the development of weights for items of this questionnaire, however, Quirk and Jones state that "asthma can have considerable restrictions on the physical and social aspects of the lives of patients with this chronic disease; it impairs their quality of life". The questionnaire is completed by the patients, and consists of 76 items divided into three categories and dimensions: respiratory symptoms, activities that cause or are limited by breathlessness (physical dimension) and psychological and social impacts on daily life (psychological/social dimension). Subscale scores as well as an overall score can be produced, based on a summation of weighted items. The weights provide an estimate of the distress associated with the symptom or state described in each item. The aim was to provide a scale suitable for clinical trials. It is designed for respiratory disease in general; it could be used for patients with
either COPD or asthma. The Asthma Quality of Life Questionnaire (AQLQ),\(^{97,98,109,110}\) was developed by the same research-group which developed the CR(D)Q. A clear definition of quality of life is not presented. However the first two out of seven criteria and characteristics presented to be essential for developing the questionnaire were that "both physical and emotional health should be measured" and that "items must reflect areas of function that are important to patients themselves".\(^{97,p.76}\) It contains 32 items which can be divided in the following subscales and dimensions: symptoms, activity limitation, exposure to environmental stimuli (physical dimension) and emotional functioning (psychological dimension). In addition to the four subscale scores, an overall score can also be calculated. An interview or a patient-completed format can be used.\(^{109}\) It was also developed to be suitable in clinical trials and to be sensitive to small within subject changes over time. It is meant for asthmatic patients. There is a strong emphasis on the physical dimension, and the activity subscale is partly individualised with the same advantages and disadvantages as the breathlessness subscale of the CR(D)Q of Guyatt et al..

Another Asthma Quality of Life Questionnaire (A-AQLQ)\(^{99}\) was developed in Australia. No explicit definition of the concept of quality of life is presented on the basis of which the questionnaire was constructed. However, in discussing the several stages of the development of the scale, Ware is quoted by the authors, as stating that quality of life scales should encompass physical, mental, social and role functioning, as well as general health perceptions. They concluded that these domains were all included in the initial stages of development.\(^{99}\) It is a self-administered, 20 item questionnaire, with one overall score and the following four subscale scores reflecting four dimensions of quality of life: breathlessness & physical restrictions (physical dimension); mood disturbances (psychological
dimension); social disruption (social dimension); and, concerns for health ('other'
dimension). It was developed in such a way that changes in individuals and
differences between individuals and groups were discernible.

The Life Activities Questionnaire for Adult Asthma (LAQAA)\textsuperscript{100} is meant to assess the performance of common life activities in adults with asthma. It must be distinguished somewhat from the above mentioned instruments because the authors stress the fact that the questionnaire in itself is not a quality of life-questionnaire, but can be used as a component of a battery of quality of life instruments. The authors discuss the diversity of definitions of quality of life and conclude that physical functioning is a dimension that is included in the majority of quality of life instruments. They consider the assessment of everyday activities in asthma as very important, because these can change and be restricted as a result of this intermittent disease. The questionnaire consists of 70 items, in 7 categories: physical activities; work activities; outdoor activities; emotions and emotional behaviour interacting with asthma and resulting in restricted activities; home care; items relating to eating and drinking; and miscellaneous activities. The reliability and validity of this questionnaire were tested and proved to be solid. The authors propose two potential aims of the questionnaire, first it can help to assess a wide array of activities in which adult asthmatics might be restricted, and second, as mentioned before, as a component in a set of instruments to assess quality of life of patients with asthma.

The global content and validity of the first four questionnaires presented in Table 3.3 (the CR(D)Q, LWAQ, (S)GRQ, and AQLQ), are discussed in detail by Hyland.\textsuperscript{106} He concluded that these questionnaires are broadly similar, but differ in the content and style of the items, possibly due to differences in methods of selecting and refining the items and that the extent to which these differences affect performance is not yet known.
Content and construct validity of all the above-presented disease-specific questionnaires is claimed by their developers. Some questionnaires however, contain only a limited number of items concerning daily life, which can be influenced by the disorder (CR(D)Q, (S)GRQ, AQLQ). The LWAQ of Hyland and the A-AQLQ of Marks et al. are instruments that in our view illuminate the physical and functional state as well as the psychological and social functioning of the patient. The LAQAA, although restricted to activities, also covers a broad range of aspects of quality of life.

The construct validity of the CR(D)Q, LWAQ, (S)GRQ, and AQLQ is put in doubt by Hyland. He argues that since none of the authors gives a detailed description of quality of life, it is difficult to assess how well each questionnaire measures this construct. The differences in content (content of subscales and dimensions) reflect the different interpretations that the authors seem to have of the quality of life concept.

Test-retest reliability is demonstrated for all questionnaires, and four also show internal consistency (LWAQ, (S)GRQ, A-AQLQ, and LAQAA). All questionnaires are developed for use in clinical trials and sensitivity for change has been demonstrated for five out of six; responsiveness for change is not yet demonstrated for the LAQAA. The research-group of Guyatt even established ranges within which a minimal clinically important difference (MCID) should fall.

Hyland, however, states these findings should not be overemphasised because the precise nature of change which is being affected is not quite clear from current research with these questionnaires.

Looking at the patient group for which these disease-specific quality of life questionnaires were developed, it can be concluded that most are applicable for, moderate to severe, asthmatic patients. The LAQAA was also developed
for asthmatic patients (diagnosed in accordance with the criteria established by the American Thoracic Society), but no further information is presented on the origin of these patients. The (S)GRQ\textsuperscript{94,95,96} addresses asthmatic as well as COPD-patients, the CR(D)Q\textsuperscript{8,9,91} seems specifically appropriate for COPD-patients. In developing the LWAQ, Hyland\textsuperscript{92,93} addressed patients in general practice settings, probably suffering from mild to moderate asthma.

**Discussion**

In this paper a review is presented of empirical studies on quality of life of CNSLD patients, with the objective of getting insight into the state of the art of this field of research. Special attention is paid to the definitions and operationalisations of the concept of quality of life and to the instruments used to assess quality of life, including recently developed disease-specific quality of life-questionnaires, taking into account the aims of the research.

As CNSLD is a chronic disease with considerable prevalence and mortality rates, the ability to adequately assess its consequences for quality of life is increasingly very important.

However, in reviewing the literature on quality of life in CNSLD it must be concluded that only little attention is paid to theories on this topic. As a result a diversity of approaches to this concept exist in quality of life research in CNSLD. A possible explanation for this may be the fact that most research in this field often results directly from clinical and practical problems.

*Definitions and operationalisation of quality of life.* In research on quality of life in CNSLD, overall definitions of this concept are mostly lacking. This is even the case in recent publications on the development of disease-specific quality of life
questionnaires for CNSLD-patients. In general operational definitions are used for 'quality of life', in terms of the dimensions that are measured and only in a minority of studies. This absence of definitions of the concept of quality of life is also found in reviews of, for example, cancer research, and seems to be a consequence of the absence of a well-developed theory of quality of life. Quality of life may nowadays be an important outcome measure in health research; its conceptualisation is still rather elusive. This is also emphasised by Cree who summarised a diversity of definitions of quality of life, which are being proposed by prominent investigators on the topic.

The few operational definitions that are presented in studies resulting from our literature review generally include physical, psychological and social functioning, the three dimensions that should, according to the literature on quality of life, minimally be assessed in quality of life research. Physical functioning, the most prominent consequence of the disease, is the dimension most frequently measured. Some studies draw conclusions about quality of life, based on physical functioning only, whereas in other studies assessment of this dimension is wholly lacking. The social dimension is most frequently neglected; about forty percent of the authors did not include social functioning in their operationalisation of quality of life. This is also shown in the publications on the disease-specific questionnaires: in two out of the six questionnaires no social dimension is included.

The variety in operationalisations of quality of life was also illustrated by the approaches of measurement within each dimension. This shows that, as a straightforward theory and definition of quality of life is lacking, choices on its operationalisation mostly seem to be based on intuition. This also seems to be the case for the recently developed disease-specific questionnaires.
Type of questionnaires used to assess quality of life. More than half the studies use generic quality of life or, parts of, psychological or psychiatric questionnaires. The latter are especially used in research that took place in the first part of the eighties, when adequate quality of life-questionnaires were lacking. Disease-specific questionnaires, however, seem to become more widely used in recent research. Seventy-five percent of the studies documenting quality of life with disease-specific questionnaires took place in the nineties. The recent availability of quality of life-questionnaires, specifically for CNSLD-patients, is of course an important cause for these developments.

Although it has been concluded in some studies that generic quality of life questionnaires might not be sensitive enough to detect the specific problems of CNSLD patients or to detect changes in functioning (for example after interventions), research using these questionnaires is still useful. It gives the opportunity to compare quality of life-data with data from healthy persons as well as persons with other chronic diseases. Research in the field of chronic diseases has shown that, in general, quality of life of CNSLD-patients is more impaired than that of patients with several other chronic diseases.

The combination of generic and disease specific questionnaires is made in a very small proportion (less than one percent) of the studies only. Research using generic as well as disease-specific questionnaires should be stimulated because, in addition to combining the advantages of both types of questionnaires this kind of research can further illuminate the psychometric characteristics of these types of questionnaires in the same population.

Aims of quality of life research. One fourth of the studies on quality of life in CNSLD was classified as descriptive in nature. This kind of research can be very meaningful in giving insight in the impact the disease has on the patients' daily
life. It was concluded that CNSLD-patients experience impaired quality of life in many aspects of daily life. All these publications concern studies in which quality of life-scores of CNSLD-patients were compared with norms, which were based on answers of healthy people. Most of the studies, some fifty percent, documenting the quality of life of CNSLD-patients have an evaluative character. In general, possible changes in quality of life as a result of specific treatments or therapies are studied. Rehabilitation or education programmes are seldom evaluated. Conclusions on effects of treatments on quality of life are contradictory. It appears that the choice of the questionnaire used to assess changes in quality of life might, at least in some cases, be responsible for this. Levenstein for example showed statistically significant improvements in quality of life after using a disease-specific questionnaire, which was not confirmed on a statistically significant level by generic quality of life questionnaires. This illustrates the importance of considering the purpose of a study, the specific criteria the questionnaires have to meet and, accordingly, the choice of the right questionnaire. The recently developed disease-specific quality of life questionnaires, for example, all claim responsiveness to change. However, Hyland puts these claims into perspective on psychometric grounds due to the absence of clear definitions of the concept of quality of life.

Only a very small proportion of the studies uses quality of life data to predict progression of the disease, physician's steroid prescribing decisions, and emergent use of health care. In the studies on determinants of quality of life, relationships between quality of life-scores on the one hand and indices of lung function on the other hand are prominent. In general, spirometric measures do not influence quality of life, indicating that quality of life is something quite different than a straightforward reflection of 'objective' disease-severity. Only a minority of studies was focused on gaining insight into the intercorrelations between
objective measures of disease-severity, personality characteristics and quality of life. As is shown in the field of cancer patients, this kind of studies might be of great help to formulate theories explaining the origins of quality of life of patients in general.\textsuperscript{115}

Specific CNSLD-patient populations that have been studied in quality of life research. A minority of studies documenting the quality of life of CNSLD-patients consider asthmatic patients. Most studies address patients with more chronic obstructive lung problems, such as patients with chronic lung disease, and rather severe COPD patients (hypoxemic as well as non-hypoxemic, with or without oxygen). In studies on the development of disease-specific quality of life questionnaires, however, the majority addresses asthmatic patients. The questionnaire developed by Jones et al.\textsuperscript{94,95,96} addresses asthmatics as well as COPD-patients. Although Guyatt et al.\textsuperscript{8,9,91} originally meant to develop their questionnaire for respiratory disease in general, it seems to be specifically meant for COPD-patients. In general, these questionnaires seem to be developed for patients with moderate to severe asthma or COPD. Only Hyland recruited his patient group via general practitioners, probably consisting of patients with mild to moderately severe illness.

After reviewing the literature on quality of life in CNSLD it can be concluded that the concept of quality of life is seldom clearly defined and that it is operationalised in a variety of ways. This is even true for recently developed disease-specific questionnaires, of which some only address a limited amount of domains of daily life which may be affected by the disease. Most studies on quality of life in CNSLD are of a descriptive or evaluative nature; little attention is paid to variables that may influence quality of life. Although this is not
exclusive for quality of life-research in CNSLD-patients, this again shows the lack of theory building in this field of research.

Further research is called for, which should pay more attention to theories on quality of life and may broaden the insight in the quality of life concept. Closer attention may be paid to further refining and validating existing disease-specific quality of life-measures in the area of respiratory disorders, as well as to theories explaining the determinants of quality of life of CNSLD-patients. Developments in cancer research, which focuses on intervening variables of quality of life (for example coping resources, self-esteem) and distinctions between affective and cognitive components of quality of life, may help CNSLD research.116 Further conceptual and theoretical insight in the quality of life of CNSLD patients may give insight in the needs of patients' enhance our understanding of their problems and improve the quality of care, resulting in an improvement of their quality of life.

References


