QUALITY OF LIFE AFTER RESPIRATORY REHABILITATION IN INDIVIDUALS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

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B.Sc. (P.T.), The University of British Columbia, 1994

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES

School of Rehabilitation Sciences

We accept this thesis as conforming to the required standard.

THE UNIVERSITY OF BRITISH COLUMBIA

AUGUST 1998
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Date September 29, 1998
Respiratory rehabilitation is directed toward decreasing some of the negative effects of chronic obstructive pulmonary disease (COPD), such as shortness of breath, decreased physical tolerance, and coping difficulties. Previous evaluations of respiratory rehabilitation have included quantitative quality of life (QOL) measurement; however, the inclusion of qualitative methods may provide a more comprehensive assessment of QOL. The purpose of this study is to use both quantitative methods (in the form of questionnaires) with qualitative methods (in the form of semi-structured interviews) to evaluate QOL changes in individuals with COPD after respiratory rehabilitation. Twenty-nine individuals with COPD were assessed before and after a five-week Control Phase, and after a five-week Rehabilitation Phase, using spirometry, a generic QOL questionnaire, the Medical Outcomes Study Short-Form 36 (SF-36) and a disease-specific questionnaire, the Chronic Respiratory Questionnaire (CRQ). Seven people then participated in a semi-structured interview with questions designed to determine how the participants perceived the Rehabilitation Phase, and the changes they attributed to rehabilitation. Respiratory rehabilitation improved QOL as demonstrated by increases of 22% (p=0.000) and 14% (p=0.001) in the Physical Function categories of the CRQ and the SF-36, respectively, and by an increase of 10% (p=0.000) in the CRQ’s Emotional Function category. These findings were expanded upon and complemented by the qualitative data, which described how acquiring skills and knowledge, gaining control and feeling more energetic, and expanding physical and emotional potential ultimately
impacted QOL. In summary, both the generic (SF-36) and the disease-specific (CRQ) questionnaires showed improved physical function but only the disease-specific questionnaire showed improved emotional function. The mixed-methods approach provided information not only on the magnitude of change of QOL, but also provided insight regarding the manner in which QOL is impacted in some individuals with COPD after respiratory rehabilitation.
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<tr>
<td>ADLs</td>
<td>Activities of daily living</td>
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<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
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<td>CRQ</td>
<td>Chronic Respiratory Questionnaire</td>
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<tr>
<td>FEV₁</td>
<td>Forced expiratory volume, first second</td>
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<td>FVC</td>
<td>Forced vital capacity</td>
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<td>HRQL</td>
<td>Health-related quality of life</td>
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<td>NHP</td>
<td>Nottingham Health Profile</td>
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<td>QOL</td>
<td>Quality of life</td>
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<td>QWB</td>
<td>Quality of Well-Being Scale</td>
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<td>SF-36</td>
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<td>SIP</td>
<td>Sickness Impact Profile</td>
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<td>SGRQ</td>
<td>St. George’s Respiratory Questionnaire</td>
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<td>6MWD</td>
<td>6 minute walk distance</td>
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ACKNOWLEDGEMENTS

I would like to acknowledge the following individuals and organizations who were instrumental in supporting this process. I would like to first thank all the participants of the two respiratory rehabilitation programs for volunteering for this study. Without their help and heartfelt words, especially the one volunteer who recently passed away, this study would not be possible. I would also like to thank the members of my supervisory committee, specifically Dr. Darlene Reid, Dr. Howard Burton, Dr. Isabel Dyck, and Dr. Ann Hilton, for their support and advice over the last three years. I would like to say thank you to my friends and family, and especially my husband David, for all their support and patience. Jessica Appleton, Maureen Gardiner, Cathy Hamre, and Marilyn Rodford of the Saint Mary’s Hospital Respiratory Rehabilitation Program, and Liz Brun and Linda Worley of the Ridge Meadows Hospital Respiratory Rehabilitation Program were extremely supportive of this research process and were instrumental in the recruitment of participants. Finally, I would like to acknowledge the financial contributions of the Canadian Physiotherapy Cardiorespiratory Society and the University of British Columbia Graduate Fellowships.
STATEMENT OF THE PROBLEM

Chronic obstructive pulmonary disease (COPD) is a progressive, incurable disease. Individuals with COPD have chronic airflow limitation, which results in shortness of breath, impaired gas exchange, and often bronchospasm and increased sputum production. The progressive nature of COPD results in individuals first presenting with shortness of breath on exertion, or increased respiratory infections, but as the disease process worsens, severe disability can occur. Shortness of breath, or dyspnea, limits activity tolerance, with resulting physical deconditioning and fatigue. COPD limits the ability of an individual to perform their activities of daily living, such as bathing, dressing, and walking, and can also lead to depression, anxiety, and social isolation. COPD can severely impact quality of life.

One therapeutic intervention designed for individuals with COPD is respiratory rehabilitation. Respiratory rehabilitation is an exercise and education program, usually delivered in a group format by a multidisciplinary team. Participants learn how to exercise safely and effectively, using a variety of aerobic and strengthening modalities. In addition, education information such as pathophysiology of COPD, ways of avoiding chest infections and irritants, energy conservation, medication use, stress management, and oxygen therapy guidelines are provided. Respiratory rehabilitation works to improve quality of life by encouraging the participants to gain greater control over their lives, as well as improving knowledge and physical function.

Traditionally, respiratory rehabilitation has been evaluated using physiological outcomes, such as lung function and exercise tests. More recently, quantitative
measures of quality of life have been incorporated in respiratory rehabilitation evaluation. These measures, usually in the form of questionnaires completed by the participants, attempt to assess quality of life by asking questions regarding physical, emotional, social and psychological function. The focus is on disability rather than impairment. This shift in focus is appropriate, as physiological measures are not sensitive to day-to-day changes in disability with COPD. But are these questionnaires able to comprehensively evaluate quality of life changes? Do participants experience improvements in various aspects of quality of life that are not captured by these questionnaires? Are there alternate forms of quality of life assessment?

Utilizing mixed-methods research may be one way to improve the completeness of quality of life data collection. Mixed-methods research involves the incorporation of both quantitative and qualitative methodologies within the same study. Quantitative methods such as standardized measures, random sampling and statistical analysis are combined with qualitative methods such as semi-structured interviews, purposive sampling and identification of themes within the data. Although quantitative QOL questionnaires provide information related to the kinds of changes that occurred, the addition of qualitative interviews can be very effective at providing insight regarding how some subjects changed. Qualitative interviews may also capture those aspects of quality of life change not measured by questionnaires.

Therefore, the purpose of this study is to use both quantitative measures, in the form of questionnaires, with qualitative methods, in the form of semi-structured interviews, to evaluate quality of life changes in individuals with COPD after respiratory rehabilitation.
Respiratory rehabilitation incorporates several types of therapeutic interventions to bring about change, including: exercise training, behavior modification, social support, counselling, and education. Each of these interventions may bring about changes in quality of life. Understanding if and how respiratory rehabilitation impacts quality of life is crucial for program development, as well as the improvement of current programs. As respiratory rehabilitation works to improve physical function, awareness, and control over the disease process, these potential benefits may result in more active, informed patients and more effective health care utilization. COPD has a tremendous impact on the health care system, as it affects more than 14 million people in the United States and is the fourth leading cause of death. Effective health care utilization may reduce the number of emergency room visits and hospital admissions and could result in large savings of health care resources.

In order to improve the effectiveness of respiratory rehabilitation programs, it would be beneficial to gain an accurate picture of the benefits of respiratory rehabilitation; specifically, the changes in quality of life. Mixed-methods research would aid in this goal, by providing not only quantitative data that may be generalizable to the COPD population, but by also providing qualitative information on the experiences of some of the individuals. Additionally, the feedback gained from the interviews may lead to further refinement of the quality of life questionnaires, if the interviews show areas of quality of life not comprehensively assessed by the quantitative measures. Finally, this study will illustrate how mixed-methods research can be utilized in program evaluation, regardless of the patient population.
REFERENCES

Chapter 1. Quality of Life and COPD

INTRODUCTION

Many health care professionals have the responsibility of providing care to those with chronic illness. Individuals with chronic obstructive pulmonary disease (COPD) are members of just one patient population who require long-term care, including education, exercise, medical management, counseling, and palliative care. For those working with people with COPD, providing the best care means helping the individual maintain or achieve the greatest quality of life possible. For many patients, this care is often in the form of medications designed to make breathing easier. However, as the disease progresses individuals with COPD are often referred to exercise and education programs, known as respiratory rehabilitation, in order to ameliorate the disabling symptoms that impact life quality. Quality of life (QOL) as an outcome measure is therefore becoming part of the clinical evaluation process in respiratory rehabilitation. This chapter will provide background information on issues surrounding QOL and its assessment, with particular emphasis on COPD and respiratory rehabilitation. In addition, it will briefly introduce the research study designed to assess QOL in individuals with COPD after respiratory rehabilitation.

The first section will introduce the concept of quality of life, as well as issues surrounding its measurement with questionnaires. The second section will then discuss COPD, including pathophysiology, physical limitations and psychosocial issues, in order for the reader to have an awareness of the complexity of the disease, including the
manner in which QOL is often affected. Specific QOL questionnaires used in the COPD population will be analyzed in the third section, including details on the selection of the appropriate questionnaire for the clinical, or research setting. The fourth section will comment on the limitations of using quantitative measures of QOL, and will discuss how the combination of both quantitative and qualitative methodologies may provide a better understanding of QOL in COPD. The final sections of this chapter will describe respiratory rehabilitation, including the components that make up respiratory rehabilitation and the manner in which respiratory rehabilitation may impact QOL in COPD. The overall objectives, hypothesis and specific aims of this study will then be stated.

QUALITY OF LIFE - MEASURING A COMPLICATED CONCEPT

In 1947, the World Health Organization defined health as being “not only the absence of infirmity and disease, but also a state of physical, mental, and social well-being.” In spite of this seemingly holistic approach to health and wellness, medical interventions at that time tended to be focussed on curing disease, as groundbreaking advances in medicine and surgery were developed. The outcome measures of interest were often focussed on either cure or mortality, opposite ends of the spectrum of health. Promoting quantity of life, or longevity, were the key outcomes of health-related therapeutic interventions.

Over the last several decades, the focus of health care has changed. The ability to control infectious disease has improved and there have been numerous advances in
surgical techniques. Consequently, medicine’s ability to prolong life has created a new era in health care. Individuals who once may have died from their illness are now living longer and hopefully, better lives. It was estimated in 1990 that one-sixth of Americans, or 43 million people, were affected by chronic illness. Chronic illness accounts for one-third of the years of potential life lost before the age 65. No longer can outcome measures be focussed purely on cure or mortality; these measures are not sensitive to changes in the lives of those with chronic disease. Life quality may now become the motive for most aspects of health care.

In response to this perspective of the purpose of health care, alternative measures capable of measuring aspects of (QOL) and health status were developed. Spitzer notes that prior to 1975, the term ‘quality of life’ did not exist in medical databases, except in editorials. Early QOL measurement tools focussed on physical function, usually the ability to perform activities of daily living (ADLs). The Karnofsky Scale of Performance Status, developed in 1948, and the Katz Activities of Daily Living Scale, developed in 1963, are two examples. These measures introduced the relatively novel idea that physical functioning is an important aspect of life and should be included in the clinical evaluation, in addition to physiological measures.

Presently in 1998, literally dozens of QOL measures are now available for use. How do these measures differ from those early physical function measures? How is QOL defined? and who defines it? What are the implications for its use in chronic illness? As the term ‘quality of life’ and the use of QOL measures become a standard feature of clinical research, it is important to avoid treating this complex subject as simply another ‘fad’, and to have a clear definition and understanding of the many
issues involved.

**Definition of Quality of Life**

'Quality of life', 'health status', 'perceived well-being' and 'functional status' all are terms that are used interchangeably in health care literature today. It appears that in the absence of consensus, authors often indiscriminately select a term, often without defining the term in the context of the article. Part of this confusion relates to the complexity of the subject itself. QOL is an intangible and dynamic concept. Asking for one definition for QOL is tantamount to expecting a consensus on what 'love' is. Nevertheless, several authors have published definitions on what they believe to be QOL (Table 1.1). Upon examination of these definitions, certain consistent themes do appear. Most agree that QOL has several key components: physical status, emotional status, social well-being, as well as other attributes such as happiness, financial security, and job satisfaction. Jette\(^5\) uses Engel’s biopsychosocial model to represent aspects of QOL (Figure 1.1). In this model, QOL is separated into three main categories, each with several subcategories. The use of the circle to symbolize QOL reinforces the lack of hierarchy in this concept. For each individual, the impact of one subcategory on the overall QOL is unique to the person; no one category can be said to be dominant, in an individual or across a population. Engel’s\(^5\) model depicts one comprehensive interpretation of QOL.

Readers will often see the term 'health-related quality of life' (HRQL). How does HRQL differ from QOL in general? There is no clear answer. Authors use the term HRQL to mean specifically QOL as it is affected by health status. Using HRQL instead
Table 1.1 Definitions of ‘quality of life’.

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<tr>
<td>Vetters⁶</td>
<td>The degree of satisfaction that an individual feels with his or her life and surroundings.</td>
</tr>
<tr>
<td>Hornquist⁷</td>
<td>The degree of need satisfaction within the areas of the physical, psychological, social, activity, material, and structural needs. Individual experiences of needs including aspired satisfaction should be considered.</td>
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<tr>
<td>Ferrans⁸</td>
<td>A person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.</td>
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<tr>
<td>Bousquet⁹</td>
<td>Quality of life is a concept that includes a large set of physical and psychological characteristics assessing problems in the social context of life style.</td>
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<tr>
<td>Curtis¹⁰</td>
<td><em>(defining health-related quality of life)</em> Measures the impact of an individual’s health on his or her ability to perform activities of daily life. May include:</td>
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<tr>
<td></td>
<td>♦ Emotional functioning (mood changes and other psychiatric symptoms)</td>
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<td></td>
<td>♦ Social role functioning (employment, home management, social, or family relationships)</td>
</tr>
<tr>
<td></td>
<td>♦ Activities of daily living (self-care skills and mobility)</td>
</tr>
<tr>
<td></td>
<td>♦ Ability to enjoy activities (hobbies and recreation)</td>
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Figure 1.1 Engel’s biopsychosocial model depicting aspects of quality of life. From: Jette AM. Using health-related quality of life measures in physical therapy outcomes research. Phys Ther 1993;73:528-537.
of QOL implies that although it is recognized that QOL can be impacted by many factors other than health (for example, job satisfaction), the measurement of QOL by a particular instrument may focus only on health-related factors.

Attributes of Quality of Life Questionnaires

QOL is usually measured with an instrument, i.e. a questionnaire. QOL instruments are often separated into categories, or domains, reflecting the different attributes which impact QOL, such as 'physical health' or 'happiness'. Questionnaires can be as short as 20 questions long, or have over 100 questions. Although there are exceptions, QOL questionnaires are usually self-reported, which means that the individual under assessment answers the questionnaire, instead of a caregiver, health care professional, or family member. Although most questionnaires are considered self-report, they can either be interviewer-administered or self-administered. Interviewer-administered questionnaires usually involve the interviewer asking the individual the questions, either in person, or over the phone. Self-administered questionnaires require the individual to read the questions and mark his or her answer.

Self-report questionnaires reflect the commonly held viewpoint that QOL is best determined by the individual and not by another third-party. When an individual is unable to complete a questionnaire due to decreased cognitive function, lowered level of consciousness, or inability to understand the questionnaire, assessment of QOL becomes more difficult. Measuring QOL in children or those who are developmentally delayed could be controversial for this reason.

QOL questionnaires can be separated into several subcategories.
Questionnaires can either be indexes or profiles, and either generic or disease-specific. An index questionnaire is one in which the questionnaire is calculated and then reduced to one score. The Quality of Well-Being Scale\textsuperscript{14-16} is one example. The range of possible scores for the Quality of Well-Being Scale is from 0 (death) to 1 (healthy). The index score does not give a breakdown of the relative contributions of each domain to QOL. Index scores are often helpful when comparing between different patient populations, but they are less useful to those who require a comprehensive understanding of how QOL is affected in a given individual or population.

Profile QOL questionnaires provide a detailed breakdown of the components of QOL. Reflecting the fact that QOL is a composite of several attributes, a profile QOL questionnaire consists of separate domains. Each domain can be individually scored, which allows for within-subject comparison between domains. For example, an individual may show decreased physical health, but his or her emotional health score may be less affected. His or her overall QOL score is still less than normal, but the profile questionnaire provides information on the specific content area in which QOL is affected. The Sickness Impact Profile\textsuperscript{17} is one example of a profile QOL questionnaire. Profile QOL questionnaires may provide an overall score of QOL, similar to an index questionnaire.\textsuperscript{17,18}

In addition to index or profile, QOL questionnaires can also be categorized as either generic or disease-specific. Generic measures are applicable across different types and severities of diseases, as well as different gender, socioeconomic, and some cultural groups.\textsuperscript{18} It should be noted, however, that generic measures are designed for use in different groups, but have not necessarily been tested in all subpopulations. The
Medical Outcomes Study Short Form 36 (SF-36)\textsuperscript{19} is an example of a generic instrument. Generic QOL measures are excellent for comparing QOL between patient populations, however, they may lack the sensitivity to distinguish subtle changes in QOL \textit{within} a patient population\textsuperscript{18} (for brief definitions of validity, reliability, and sensitivity, see Table 1.2). For example, in COPD, shortness of breath is a common clinical feature that impacts life quality. If a generic measure does not ask questions regarding ease of breathing, it may be unable to identify changes in QOL due to this symptom. In addition, generic measures may ask questions that are totally irrelevant to the patient population. Questions regarding employment may not be crucial if most of the patient population is elderly, or are children. This lack of sensitivity has led to the criticisms of low content validity for generic QOL measures.\textsuperscript{18}

Disease-specific questionnaires are designed in an effort to improve sensitivity to QOL changes in a specific population. These questionnaires ask specific questions regarding the usual signs and symptoms of a disease. The Chronic Respiratory Questionnaire\textsuperscript{20} is an example of a disease-specific questionnaire for individuals with chronic airflow limitation. Disease-specific questionnaires are often more sensitive to subtle changes in QOL changes,\textsuperscript{18} but may not be appropriate for QOL assessment across different patient populations.

\section*{Ethical Considerations of Quality of Life Measurement}

A QOL questionnaire must be scrutinized in terms of its psychometric properties (i.e. reliability, validity, and responsiveness). In addition to these psychometric considerations, researchers and clinicians must be aware that no one
Table 1.2. Definitions of Validity, Reliability, and Responsiveness

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<td>Does the instrument appear to be measuring what it is intended to measure?\textsuperscript{21}</td>
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<tr>
<td>Construct validity:</td>
</tr>
<tr>
<td>Does the instrument have good comparison with other measures, and are there logical relationships between the measure and the characteristics of the patient group?\textsuperscript{21}</td>
</tr>
<tr>
<td>Content validity:</td>
</tr>
<tr>
<td>Is the domain of interest comprehensively sampled by the items in the instrument?\textsuperscript{21}</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reliability:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test-retest reliability:</td>
</tr>
<tr>
<td>Do repeated measurements show more or less the same results on stable patients?\textsuperscript{21,22}</td>
</tr>
<tr>
<td>Internal Consistency:</td>
</tr>
<tr>
<td>Do items within the same domain yield similar scores?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Responsiveness:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity:</td>
</tr>
<tr>
<td>Is the instrument able to accurately detect change in those that did change?\textsuperscript{22}</td>
</tr>
<tr>
<td>Specificity:</td>
</tr>
<tr>
<td>Is the instrument able to discriminate between those that did change and those that didn’t?\textsuperscript{22}</td>
</tr>
</tbody>
</table>
questionnaire, regardless of psychometric properties, will ever be able to

*comprehensively* assess QOL in an individual. Okubadejo et al\textsuperscript{23} noted:

(quality of life) questionnaires...attempt a comprehensive coverage, but for reasons of length and practicality, they cannot address all of the possible disturbances that patients may suffer...A distinction should therefore be drawn between the quality of life of an individual...and the standardised estimate of their impaired health provided by a quality of life questionnaire.

This distinction is often overlooked in health care literature. Health care professionals and payers must recognize the limitations of a QOL measure. Failure to do so may result in unethical uses of the questionnaire. Dean\textsuperscript{24} raised some thought-provoking issues on the ethical use of QOL measurement when she asked:

*For what purpose is quality of life to be used?...Will quality of life be used as a means to justify limiting treatment options for individuals?...Will quality of life be used as a means for forcing treatment on someone who refuses?*”

The development and use of QOL measures is still in its infancy; therefore, serious decisions such as withholding treatment, or allocation of health care resources, should not be based solely on a score from a QOL measure. Future debates will determine the place of QOL measures in the health care system.

Currently, QOL measures are often used to a) describe a population or individual (using *descriptive* instruments); b) characterize the QOL attributes between patient populations (using *discriminative*\textsuperscript{21} instruments) and c) assess the impact of therapeutic interventions on QOL (using *evaluative*\textsuperscript{21} instruments). All of these purposes have been demonstrated in the COPD population.
In order to understand the use of QOL measures in COPD, it is helpful to know how this disease impacts individuals. The following section will provide a brief description of the physical and psychosocial impact of COPD.

COPD – PATHOPHYSIOLOGY AND PSYCHOSOCIAL IMPACT

Definitions & Pathophysiology

Chronic obstructive pulmonary disease (COPD) refers to several lung diseases that are often associated with severe disability. The American Thoracic Society defines COPD as being:

A disease state characterized by the presence of airflow obstruction due to chronic bronchitis or emphysema; the airflow obstruction is generally progressive, may be accompanied by airway hyperreactivity, and may be partially reversible.\textsuperscript{25}

Although COPD consists of several different diseases with different pathophysiological mechanisms, limitation of expiratory airflow is the predominant feature of these lung conditions.

As indicated by the above definition, the two most common chronic obstructive pulmonary diseases are \textit{chronic bronchitis} and \textit{emphysema}. Chronic bronchitis is an inflammatory disease of the airways. Diagnosis is made if the patient has a cough productive of sputum for at least three consecutive months in a year, for at least two consecutive years, in a patient in which other causes for the cough have been ruled out.\textsuperscript{25} Enlargement of mucous glands in the airways leads to increased sputum production, which can cause airway obstruction and plugging. In addition, the airways
can display an inflammatory process\textsuperscript{25} and bronchoconstriction due to spasm and hypertrophy of the smooth muscles. All of these factors can contribute to airflow limitation.\textsuperscript{26}

Emphysema is defined as “abnormal, permanent enlargement of the airspaces distal to the terminal bronchioles, accompanied by destruction of their walls and without obvious fibrosis.”\textsuperscript{25} This destruction of alveoli renders them incapable of effective gas exchange. In addition, destruction and decreased recoil of the alveolar walls leads to expiratory airflow limitation, because the more compliant alveolar walls are unable to tether open the small airways during expiration. Thus, airway collapse and air trapping occurs in the distal alveoli, which leads to hyperinflation. While chronic bronchitis and emphysema are considered separate disease processes, most individuals with COPD have some element of both conditions.\textsuperscript{27}

**Epidemiology & Risk Factors**

In 1995, the American Thoracic Society\textsuperscript{25} estimated that approximately 14 million Americans have COPD. Gender differences are apparent; age-adjusted prevalence rates for men were 110 per 1000 in 1985, showing only a slight increase from 1979-1985, whereas for the same time period COPD prevalence for women increased 30% to 119 per 1000 persons.\textsuperscript{25} Mortality rates have also shown increases; the mortality rate for COPD rose 32% between 1979 and 1991, making it the fourth leading cause of death overall.\textsuperscript{25}

Smoking is the leading cause of COPD; 80% to 90% of COPD diagnoses in the United States can be linked to smoking.\textsuperscript{28} The diagnosis of COPD can also be linked
to the patient's exposure to occupational and environmental dusts or gases, or a congenital enzyme disorder, known as alpha-1 antitrypsin deficiency. However, emphysema due to alpha-1 antitrypsin deficiency makes up less than 1% of all cases of COPD.²⁵

Clinical Features of COPD

The chronic airflow obstruction in COPD results in various physical signs and symptoms (Table 1.3). COPD presents along a continuum, with symptoms ranging from mild to severe. Airflow obstruction is assessed using pulmonary function measurements. The forced expiratory volume in the first second (FEV₁) is the measurement most commonly used to assess disease severity, and prognosis. The FEV₁ is measured by having the individual forcefully expire a maximum breath down to residual volume, and calculating the volume of air expired in the first second of the maneuver. The measurement is then compared with the values obtained from a healthy individual of the same gender, age, and height, and is usually expressed as a percentage of the predicted value. The American Thoracic Society²⁹ uses the FEV₁ as a means to stage individuals with COPD because the FEV₁ is the best indication of airway obstruction (Table 1.4)

A common presentation of COPD is shortness of breath, also known as dyspnea. The physiological mechanism leading to dyspnea is unclear, but it is considered to be due to the increases in respiratory muscle tension related to increases in the work of breathing, stimulation of pulmonary J receptors, or alteration in the PaO₂ or PaCO₂ homeostasis. Although the sensation of dyspnea is variable in mild-to-
Table 1.3. Common Clinical Features of Chronic Obstructive Pulmonary Disease.

<table>
<thead>
<tr>
<th>History</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Dyspnea, usually on exertion$^{25}$</td>
</tr>
<tr>
<td>• Decreased physical activity$^{25}$</td>
</tr>
<tr>
<td>• Sputum production, usually $&lt; 60$ ml per day$^{30}$</td>
</tr>
<tr>
<td>• Frequent respiratory infections$^{31}$</td>
</tr>
<tr>
<td>• Loss of appetite and/or weight change$^{25}$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Barrel-chested, clubbing, cyanosis$^{25}$</td>
</tr>
<tr>
<td>• Respiratory accessory muscle use$^{25,30}$</td>
</tr>
<tr>
<td>• Decreased breath sounds; sometimes crackles and wheezes on auscultation$^{30}$</td>
</tr>
<tr>
<td>• Right heart failure and cardiac rhythm irregularities in advanced lung disease$^{25}$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Test Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Airflow obstruction, as measured by pulmonary function tests$^{25}$</td>
</tr>
<tr>
<td>• Hyperinflation, especially in emphysema, evident on chest X-ray$^{25}$</td>
</tr>
<tr>
<td>• Hypoxia and hypercapnia$^{25}$</td>
</tr>
<tr>
<td>• Weakened and/or fatigued respiratory muscles$^{32}$</td>
</tr>
</tbody>
</table>
Table 1.4 American Thoracic Society Guidelines for COPD Disease Severity

<table>
<thead>
<tr>
<th>FEV₁ (percent predicted)</th>
<th>Disease Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>70% - 100%</td>
<td>Mild COPD</td>
</tr>
<tr>
<td>60% - 69%</td>
<td>Moderate COPD</td>
</tr>
<tr>
<td>50% - 59%</td>
<td>Moderately Severe COPD</td>
</tr>
<tr>
<td>34% - 49%</td>
<td>Severe COPD</td>
</tr>
<tr>
<td>&lt; 34%</td>
<td>Very Severe COPD</td>
</tr>
</tbody>
</table>

COPD = Chronic Obstructive Pulmonary Disease; FEV₁ = forced expiratory volume, first second.
moderate COPD, it is considered progressive and unvarying in most individuals with advanced COPD.\textsuperscript{33}

As the disease becomes more severe, impaired gas exchange is often apparent. Individuals with severe COPD are often hypoxemic (partial pressure of O\textsubscript{2} in the arterial blood (PaO\textsubscript{2}) < 80 mm Hg) and hypercapnic (partial pressure of CO\textsubscript{2} in the arterial blood (PaCO\textsubscript{2}) > 45 mm Hg). Chronic hypoxemia is associated with an increase in mortality;\textsuperscript{34,35} therefore, individuals with a PaO\textsubscript{2} of less than 55 mm Hg are often placed on 24 hour supplemental oxygen.\textsuperscript{34} Oxygen therapy improves survival rates and allows for increased physical activity.\textsuperscript{35}

Individuals with COPD can also have frequent bacterial respiratory infections. Infections are usually due to \textit{Streptococcus pneumoniae}, or \textit{Haemophilus influenzae}\textsuperscript{34} and are usually treated with oral antibiotics.

COPD is often associated with significant functional limitations. As the disease process continues and the experience of dyspnea becomes uncomfortable, individuals with COPD often reduce their physical activity, resulting in deconditioning and worsening dyspnea. They can have difficulty with their activities of daily living such as doing housework, showering, and dressing.\textsuperscript{36} However, although there is a tendency for those with severe lung disease to have significant levels of disability, the correlation between disease severity and disability is variable. In COPD, someone with relatively poor lung function can still be relatively active and independent, whereas someone else with apparently minimal lung disease can be extremely debilitated. Weaver et al\textsuperscript{37} noted, in their 1992 review paper on the physiological and psychological variables in COPD, that researchers have been able to demonstrate only ‘modest’ relationships
between pulmonary function and functional status. For example, tests of functional activity, such as the six-minute walk distance test (6MWD)\textsuperscript{38} have shown that individuals with COPD have significant restrictions in their walking tolerance.\textsuperscript{38,39} The 6MWD is considered to be a more effective measure of functional ability than a maximal exercise test.\textsuperscript{38} However, studies which have attempted to correlate six minute walking distance with measures of lung function, such as FEV\textsubscript{1}, have shown conflicting results. Jette et al\textsuperscript{36} showed a correlation of $r = 0.46$ between the 6MWD and FEV\textsubscript{1}. Alonso et al\textsuperscript{40} had a similar finding ($r = 0.23$). Swinburn et al\textsuperscript{41} and McGavin et al\textsuperscript{42} reported correlations of 0.283 and 0.17, respectively, between FEV\textsubscript{1} and the 12-minute walking distance test. Variations in these evaluations may be due to differences in test administration, disease severity, age, and gender of the subjects. Yet it would appear that the decrease in physical function is not solely due to the progressive decline in lung function. There may be other factors that impact the physical abilities of individuals with COPD, such as level of dyspnea, deconditioning, level of family support, or other comorbidities.

**Psychosocial Aspects of COPD**

In addition to the physical limitations of the disease, there can be severe psychosocial problems attributed to COPD. Changes related to aging can also be confused with those related to COPD. Kline Leidy et al\textsuperscript{43} reported:

*Older adults with COPD face multiple challenges to successful adjustment, including the simultaneous demands associated with aging, chronic illness, and potentially disconcerting symptomatology.*
Investigators have reported a wide variety of psychosocial limitations in COPD (Table 1.5). Depression and anxiety are the most common psychological disorders occurring. The estimate of the prevalence of depression in COPD varies depending on how it was described. Agle and Baum\textsuperscript{44} stated that 74\% of COPD had superficial depression. Two studies reported that approximately 42\% of patients were primarily depressed.\textsuperscript{45,46} Regardless of the percentages, higher levels of depression are found in patients with COPD compared to healthy subjects, and it appears to be more severe than depression found in those with peripheral vascular disease.\textsuperscript{47} Depression in COPD in another study was characterized by a pessimistic outlook, as well as feelings of hopelessness and worthlessness.\textsuperscript{48}

The underlying cause of depression in individuals with COPD has not been determined. Although chronic hypoxemia has been implicated,\textsuperscript{49} McSweeney\textsuperscript{50} determined that although physiological factors were a factor, depression in COPD is mainly situational, and related to “economic hardship, loss of pleasurable activities, and difficulty with coping.” Further evidence to support this hypothesis is the fact that administration of oxygen appears to have no effect on depression in COPD.\textsuperscript{51}

Anxiety is another common psychosocial finding in COPD, although reports on the prevalence of anxiety vary widely. In addition to the discussion of the underlying mechanisms, there are also reports of anxiety prevalence in COPD ranging from 2\% - 96\%.\textsuperscript{44,46,52} Part of the confusion may relate to the variety of anxiety measures used, the range of disease severity and other characteristics in the various samples. Agle and Baum\textsuperscript{44} stated that 22 of 23 male subjects who underwent the ‘psychiatric interviews’ were considered to have “symptoms of anxiety sufficient to interfere with
Table 1.5. Cognitive and Psychosocial Attributes Frequently Seen in Chronic Obstructive Pulmonary Disease

- depression\textsuperscript{44}
- anxiety\textsuperscript{44-46}
- somatic preoccupation\textsuperscript{45}
- irritability, anger\textsuperscript{45}
- decreased ability to cope flexibly with life changes\textsuperscript{49}
- sexual dysfunction\textsuperscript{53}
- decreased perception of control\textsuperscript{54}
- loneliness\textsuperscript{55}
- social isolation\textsuperscript{56}
- difficulties with abstract reasoning and problem-solving\textsuperscript{57}
performance”. Unfortunately, the lack of a valid measure of anxiety coupled with the fact that they did not report on the disease severity of their sample limits the generalizability of their results to the COPD population. Light et al.,\textsuperscript{46} using the State-Trait Anxiety Inventory, reported that only 2% of their sample had symptoms of anxiety. Although the majority of the group had severe COPD (defined in the study as an FEV\textsubscript{1} of less than one litre), and the study used a standardized measure, the sample was comprised of men only. Prevalence rates of anxiety may have been different had they included female subjects. McSweeney et al.\textsuperscript{49} reported that individuals with severe COPD considered themselves to be more anxious than the matched normal control group. Although the researchers employed a standardized measure, the Profile of Mood States, on a large sample of 203 men and women, the fact that the sample had severe COPD limit the application of the findings to the overall COPD population. Although these three papers are often cited in research and review articles as the documentation for the overall prevalence of anxiety in COPD, it would appear that the prevalence rates of anxiety in COPD across all stages of disease severity has not been clearly determined.

The underlying mechanism of anxiety is poorly understood, and may also contribute to the difficulties of measurement. Smoller et al.\textsuperscript{52} reviewed the prevalence of anxiety in respiratory disease and concluded that the psychiatric condition ‘panic disorder’, which they considered to be severe anxiety, was ten times more prevalent in the COPD population than in the general public. They also noted that anxiety or panic attacks would be difficult to diagnose in this population, as one common symptom of anxiety is dyspnea. Whether the dyspnea causes the experience of anxiety, or the
reverse, is not yet known. However, Smoller et al.\(^5\) did note that other physiological processes, such as CO\(_2\) sensitivity, is related to the experience of anxiety, and therefore may explain the mechanism underlying the symptom in the COPD population who have CO\(_2\) abnormalities.

In addition to depression and anxiety, other cognitive and psychosocial limitations have been investigated in COPD (Table 1.5). Using data from the Nocturnal Oxygen Therapy Trial (NOTT) Group and the Intermittent Positive Pressure Breathing (IPPB) Group, Prigatano & Grant\(^5\) determined that COPD patients may have difficulties with abstract reasoning and with problem-solving. Although basic verbal skills, memory, and intelligence are relatively unaffected, simple motor activity is often slower than in normal adults of the same age. In addition, societal factors may exacerbate the psychosocial limitations in COPD. Coughing in public, shortness of breath, or oxygen use may be embarrassing and stigmatizing. Patients with COPD may curtail or discontinue certain public activities completely if they feel uncomfortable with public perceptions about their disease.

The combination of physical, psychological, and societal problems related to COPD can be extremely detrimental to QOL. It is important for physical therapists and other health care professionals to recognize and understand the multiple ways in which COPD affects an individual; COPD is more than just a breathing problem. As COPD is chronic and incurable, therapeutic interventions are designed to minimize the impact of the disease. Reardon\(^3\) stated that the primary treatment goals should include: "reduction in symptoms, increase in functional status, and improvement in QOL". Outcome measures should focus on the disabilities the patient experiences, not just on
lung function or other physiological measures. QOL measures may be appropriate outcome measures as they often assess the physical, psychological, emotional and sociological aspects of a patient’s illness experience. Although they may not be able to comprehensively analyze every aspect of QOL, they can provide an estimate of this phenomenon. Using one or two QOL measures may be less time-consuming than using battery tests (often done for psychological assessments), and therefore their use may be more feasible in the clinical setting. The following section will describe QOL measures, both generic and disease-specific, used with the COPD population.

QUALITY OF LIFE MEASURES & COPD

Measurement of QOL using standardized questionnaires is a fairly recent occurrence in clinical research on COPD. A Medline search revealed few clinical studies with QOL as an outcome measure prior to 1975. Measures of impairment, such as mortality or FEV₁, were the more common outcome measures in COPD studies, yet these outcomes are not sensitive to day-to-day changes in disability with COPD. As COPD is a chronic illness that is slow and insidious in onset, changes in daily functioning are more relevant to patient care than mortality. In addition, daily functioning is not closely related to physiological impairment so a direct measure of day-to-day changes in disability would be more meaningful than measures such as FEV₁.

Although QOL measurement may be relatively recent in COPD, a large variety of other questionnaire-based measures have been used in this population. A quick
assessment of Medline articles from 1966 to present revealed more than 50 different questionnaires. Several have assessed physiological symptoms such as dyspnea, others have addressed distinct psychological attributes, such as loneliness, social support, or depression. Measures of functional status have also been used; these measures tend to determine an individual’s ability to perform activities of daily living (ADLs). As discussed previously, QOL measures are often composite questionnaires that contain components found in these other measures. Usually, there are questions relating to physical abilities, mood, social roles, energy level, happiness, recreation, and social activities. Some may have questions relating to work ability. In COPD studies, both generic and disease-specific questionnaires have been utilized.

Selecting a Quality of Life Measure for COPD

In order to select the most appropriate questionnaire, the user must consider several questions. A popular questionnaire isn’t necessarily appropriate for all purposes. Table 1.6 lists several points to be considered prior to choosing a QOL questionnaire. It may be difficult to find a questionnaire which meets all these criteria; however, the best questionnaire for a particular clinical or research setting will satisfy the most possible points.

QOL questionnaires for COPD have been used in three different ways: a) to describe the population (descriptive purposes); 2) to compare across different populations (discriminative purposes); or 3) to assess the benefits of an intervention, usually pharmacological, educational, or rehabilitative (an evaluative purpose). The following section will describe six of the most commonly used measures in COPD;
Table 1.6. Steps to Selecting a Quality of Life Questionnaire

1. Choose a definition of quality of life, including in the definition components unique to the patient population.

2. Determine what aspects of quality of life you wish to measure, or those you expect to change with your intervention.

3. Determine:
   - Who will measure quality of life (usually the client)
   - Generic or disease-specific questionnaire
   - Index or profile questionnaire

4. Review quality of life instruments via Medline searches, bibliographies, review articles and research articles

5. Select measure(s) which:
   - Have been used in your population (consider disease severity, comorbidities, etc.)
   - Measure the aspects of quality of life you wish to measure
   - Have been shown to be reliable, valid, and responsive in your patient population
   - Are feasible to administer in your setting – enough time to administer, appropriate for age/cognitive level, simple to score.
four generic measures, as well as two disease-specific measures.

**Generic Quality of Life Questionnaires**

*The Sickness Impact Profile*

Of all generic QOL questionnaires used on the COPD population, the Sickness Impact Profile (Appendix A) has been used the most extensively. Created in the mid-1970's by Bergner et al, the Sickness Impact Profile provided one of the first behaviorally-based measures of health status. It is a 136-item questionnaire that can be either interviewer- or self-administered. The questionnaire is separated into twelve categories of activity (see Table 1.7). The individual determines if each statement describes him/her on that particular day and is related to his/her health. Each selected statement is weighted, and the total and categorical scores calculated, with a higher score indicating a decreased QOL. In addition to categorical and total scores, a physical dimension score and a psychosocial dimension score can be calculated. Validity and reliability scores across several patient populations have been reported (Tables 1.8 and 1.9).

Several descriptive, correlational, and experimental clinical studies have used the SIP as their measure of QOL. The Intermittent Positive Pressure Breathing (IPPB) Therapy Trial was one of the first randomized clinical trials to use the SIP, in 1978. Previous to this study, the creators of the SIP included individuals with COPD in their tests of reliability and validity. The SIP is considered to be a reliable and valid measure of health status, and is often considered to be the 'gold standard' of QOL questionnaires. Its use as a QOL measure in the COPD population has been
Table 1.7. Domains of the Sickness Impact Profile, the SF-36, the Quality of Well-Being Scale, and the Nottingham Health Profile.

<table>
<thead>
<tr>
<th>Measure</th>
<th>SIP</th>
<th>SF-36</th>
<th>QWB</th>
<th>NHP</th>
</tr>
</thead>
<tbody>
<tr>
<td># of Items</td>
<td>136</td>
<td>36</td>
<td>27</td>
<td>45</td>
</tr>
<tr>
<td>Time</td>
<td>20 – 30 minutes</td>
<td>10 minutes</td>
<td>15 – 20 minutes</td>
<td>20 minutes</td>
</tr>
<tr>
<td># of Domains</td>
<td>12</td>
<td>8</td>
<td>3, plus 23-item symptom list</td>
<td>6, plus 7 general questions about health</td>
</tr>
</tbody>
</table>

**Physical Domains**
- Ambulation
- Mobility
- Body Care & Movement
- Physical Functioning
- Role – Physical
- Bodily Pain
- Vitality

**Psychosocial Domains**
- Social Interaction
- Communication
- Alertness Behavior
- Emotional Behavior
- Emotional Functioning
- Role – Emotional
- Mental Health

**Other Domains**
- Sleep and Rest
- Eating
- Work
- Home Management
- Recreation and Past-times
- General Health Perception
- 23 statements of symptoms (pain, stuttering, burns, bleeding, etc.) are marked if present

**SIP**=Sickness Impact Profile; **SF-36**=Short Form 36; **QWB**=Quality of Well-Being Scale; **NHP**=Nottingham Health Profile
Table 1.8. Validity of the Sickness Impact Profile, the Short-Form 36, the Quality of Well-Being Scale, and the Nottingham Health Profile

<table>
<thead>
<tr>
<th>Validity Concurrent Validity</th>
<th>SIP</th>
<th>SF-36</th>
<th>QWB</th>
<th>NHP</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIP Physical category and FEV₁</td>
<td>( r = -0.30 )</td>
<td>( r = 0.65 )</td>
<td>( r = 0.58 )</td>
<td>( r = 0.60 )</td>
</tr>
<tr>
<td>SF-36 Physical Functioning category and FEV₁ ( ^{69} )</td>
<td>( r = 0.47 )</td>
<td>( r = 0.49 )</td>
<td>( r = 0.60 )</td>
<td>NHP Energy category and Dyspnea Visual Analogue Scale ( ^{40} )</td>
</tr>
<tr>
<td>SIP Physical category and FVC</td>
<td>( R = -0.42 )</td>
<td>( r = 0.37 - 0.52 )</td>
<td>( r = 0.41 )</td>
<td>( r = -0.45 )</td>
</tr>
<tr>
<td>SIP Total score and 6 minute walk test ( ^{62} )</td>
<td>( R = 0.51 )</td>
<td>( r = 0.41 )</td>
<td>( r = 0.41 )</td>
<td>( r = 0.64 )</td>
</tr>
<tr>
<td>SIP Total Score and Anxiety category from Hospital Anxiety and Depression Scale ( ^{62} )</td>
<td>( r = 0.37 - 0.52 )</td>
<td>( r = 0.41 )</td>
<td>( r = 0.41 )</td>
<td>( r = 0.64 )</td>
</tr>
</tbody>
</table>

SIP = Sickness Impact Profile; SF-36 = Medical Outcomes Study Short-Form 36; QWB = Quality of Well-Being Scale; NHP = Nottingham Health Profile COPD = Chronic obstructive pulmonary disease; FEV₁ = Forced expiratory volume, first second. VO₂max = maximal oxygen consumption.
Table 1.9. Reliability of Four Generic Quality of Life Questionnaires

<table>
<thead>
<tr>
<th>Reliability</th>
<th>SIP</th>
<th>SF-36</th>
<th>QWB</th>
<th>NHP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Internal Consistency</strong></td>
<td>Cronbach’s alpha = 0.94</td>
<td>r = 0.82 – 0.93 Medical patients&lt;sup&gt;71&lt;/sup&gt;</td>
<td>Not reported</td>
<td></td>
</tr>
<tr>
<td>Non-COPD patients&lt;sup&gt;17&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Test-retest Reliability</strong></td>
<td>r = 0.92</td>
<td>r = 0.63 – 0.81 Medical patients&lt;sup&gt;72&lt;/sup&gt;</td>
<td>r = 0.78 – 0.99 Mixed group of patients, including COPD&lt;sup&gt;16&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>24 hour interval, various illnesses&lt;sup&gt;17&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spearman’s r = 0.75 – 0.88; Part 1, non-COPD patients. Cramer’s alpha = 0.55 – 0.86; Part 2, non-COPD patients.</strong>&lt;sup&gt;73&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SIP=Sickness Impact Profile; SF-36=Short Form 36; QWB=Quality of Well-Being Scale; NHP=Nottingham Health Profile; COPD=Chronic Obstructive Pulmonary Disease.
questioned, however. Jones\textsuperscript{74} reported that the SIP is relatively insensitive in patients with asthma and COPD because its scores remain in the mildly abnormal range until the $FEV_1$ falls below 50% of the predicted normal; in other words, the questionnaire is not sensitive to QOL impairment until the disease becomes moderate to severe. Although the psychosocial component of the SIP has been correlated with mental health scales,\textsuperscript{62} its sensitivity to change in physical function has been challenged.\textsuperscript{75} The lack of information on what change in SIP scores reflects a clinically significant difference in the COPD population is also problematic.\textsuperscript{76} Although the SIP may be considered a gold standard by some, its usefulness in the COPD population, both as an acceptable discriminative tool and as an evaluative tool is equivocal.

\textit{The Medical Outcomes Study Short Form 36}

The Medical Outcomes Study Short-Form 36 (SF-36) was developed in 1992 by Ware and associates.\textsuperscript{19} It is a 36-item self-report questionnaire, divided into 9 categories (Table 1.7). It can be either interviewer-administered or self-administered, has been translated into several languages, and has been used to assess either acute or chronic conditions. The SF-36 takes approximately 10 minutes to complete; an advantage over the SIP. The SF-36 is also considered to be a reliable and valid instrument across several disease populations (Tables 1.8 and 1.9).

Mahler et al\textsuperscript{77} reported the validity of the SF-36 in the COPD population by showing strong correlations between the physical categories of the questionnaire, the Baseline Dyspnea Index,\textsuperscript{10} and maximal inspiratory pressure, a measure of respiratory muscle strength. Limbos et al\textsuperscript{70} reported significant correlations between the SF-36
physical domains and transplant status on a group of women awaiting transplant for a variety of chronic respiratory conditions. Reports on the SF-36’s reliability and responsiveness in COPD have not been published. Considering the number of studies presented at the 1996 and 1997 American Thoracic Society scientific meetings in which the SF-36 was used as a QOL measure in COPD (20 in all), reports on reliability and validity should be forthcoming.

The Quality of Well-Being Scale

The Quality of Well-Being Scale (QWB)\(^{16}\) is an index questionnaire used to assess QOL. It consists of three scales of function: Mobility, Physical Activity, and Social Activity, and a symptom-identification section (Table 1.7). The score from the symptom list is combined with the score from the function scales. Using a complex formula, a final score is derived, ranging from 0 (death) to 1 (healthy). The economic impact of illness and the well-life expectancy can also be calculated. Time to administer is 12-20 minutes. Administration of the questionnaire is complicated; it is recommended the assessor complete the scale.\(^{75}\) Thus, this questionnaire is not a self-report measure. Reliability and validity have been demonstrated across several disease populations, as well as with COPD (Tables 1.8 and 1.9). Although reliable and valid, the QWB’s sensitivity in the COPD population is questionable. Kline Leidy\(^{76}\) reports that in “clinical trials (of COPD), comprehensive rehabilitation and varying doses of beta agonists had no impact on QWB scores.” As other questionnaires have measured a change in QOL after similar interventions,\(^{78,79}\) the QWB may not be an appropriate evaluative tool in this population, a problem noted by other researchers.\(^{75,78}\)
The Nottingham Health Profile

The Nottingham Health Profile (NHP)\textsuperscript{80} is a generic, self-report measure developed by researchers at the Nottingham University. It is a 45-item, two part questionnaire, containing six domains: physical mobility, pain, social isolation, emotional reactions, energy, and sleep (Table 1.7). The NHP does not provide an overall QOL score; information is provided in profile format only. The NHP appears to be a valid measure of QOL in COPD patients (Table 1.8), as shown by a good relationship to other measures of dyspnea and mobility, yet similar to previous generic measures, questions regarding measurement sensitivity have been raised. van Schayck et al\textsuperscript{81} in a study of bronchodilator therapy in COPD patients was not able to detect changes in life quality between the two treatment groups, even though lung function in one group significantly declined compared to the other group. van Schayck\textsuperscript{81} attributed the similar QOL scores between the two groups to the ability of the lower lung function group to adjust to their worsening status; however, it may be true that the measure was not sensitive to the change. Inclusion of a disease-specific QOL measure may have yielded different results.

Generic measures can be useful when comparing QOL attributes between different disease populations, however, their apparent lack of sensitivity to measure change over time limits their usefulness when assessing the benefit of a therapeutic intervention. Disease-specific QOL measures for COPD may be able to address the sensitivity issue, as the questions asked are focussed to the unique experience of living with chronic airflow obstruction. Of the available disease-specific questionnaires, only
two have shown adequate validity, reliability, and responsiveness. These two disease-specific questionnaires, the St. George’s Respiratory Questionnaire, and the Chronic Respiratory Questionnaire will be discussed in the next section.

Disease-Specific Quality of Life Questionnaires

The St. George’s Respiratory Questionnaire

The St. George’s Respiratory Questionnaire (SGRQ) is a 76-item disease-specific questionnaire developed in the United Kingdom by Jones and associates. It consists of three domains: symptoms, activities, and impact (Table 1.10). The three sections are scored separately on a scale of 0 to 100%, with a higher percentage indicating worsening QOL. A total score can also be calculated. A major shortcoming of the SGRQ is that it does not have any questions relating to depression and anxiety. These clinical problems may be impacted by many therapeutic interventions for COPD, such as exercise training and behavioral modification. The SGRQ should be used in conjunction with a measure of psychological function, an opinion which appears to be shared by the creators, as they reportedly did not include psychological questions as they felt other questionnaires were available for such a purpose.

Okubadejo et al reported several significant correlations between all domains of the SGRQ and physiological measures. In addition, significant correlations between the SGRQ and the Hospital Anxiety and Depression Scale were noted. Jones et al concluded the SRDQ “had properties that make it suitable for studies designed to quantify changes in the health of patients with diseases causing chronic airflow limitation”. The SGRQ has been used as an outcome measure in
Table 1.10. Domains of the St. George’s Respiratory Questionnaire and the Chronic Respiratory Questionnaire

<table>
<thead>
<tr>
<th>Measure</th>
<th>St. George’s Respiratory Questionnaire</th>
<th>Chronic Respiratory Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td># of Items</td>
<td>50</td>
<td>20</td>
</tr>
<tr>
<td>Time to Administer</td>
<td>20 minutes</td>
<td>20 – 30 minutes (1st administration) 15 minutes (2nd administration)</td>
</tr>
<tr>
<td># of Domains</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Physical Domains</td>
<td>❧ Symptoms  ❧ Impact  ❧ Activity</td>
<td>❧ Dyspnea  ❧ Fatigue</td>
</tr>
<tr>
<td>Psychosocial Domains</td>
<td>None</td>
<td>❧ Emotional Function  ❧ Mastery</td>
</tr>
</tbody>
</table>
Table 1.11. Validity and Reliability of the St. George’s Respiratory Questionnaire and the Chronic Respiratory Questionnaire

<table>
<thead>
<tr>
<th></th>
<th>St. George’s Respiratory Questionnaire (SGRQ)</th>
<th>Chronic Respiratory Questionnaire (CRQ)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Validity</strong></td>
<td>$r = 0.59$ SGRQ-symptoms category and Medical Research Council respiratory symptom questionnaire – cough category $^{78}$</td>
<td>$r = 0.55$, CRQ and FEV$_1$ $^{79}$</td>
</tr>
<tr>
<td></td>
<td>$r = 0.59$ SGRQ-activity category and Six-minute walk test $^{78}$</td>
<td>$r = 0.52$, CRQ and Six-minute walk test $^{79}$</td>
</tr>
<tr>
<td></td>
<td>$r = 0.62$ SGRQ-total score and Hospital Anxiety &amp; Depression Scale – depression category $^{23}$</td>
<td>$r = 0.66$, CRQ – Dyspnea category and Dyspnea Visual Analog Scale $^{79}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$r = 0.50$, CRQ – Emotional Function category and Symptom Checklist questionnaire – Anxiety category $^{79}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$r = 0.69$ CRQ – Emotional Function category and Center for Epidemiologic Studies Depression Scale $^{79}$</td>
</tr>
<tr>
<td><strong>Test-retest Reliability</strong></td>
<td>Interclass * correlation (ICC) = 0.92 $^{78}$</td>
<td>$r = 0.68 - 0.90$ for three of four domains $^{85}$</td>
</tr>
</tbody>
</table>

*ICC = reliability coefficients that are used when two or more repeated measures have been obtained. FEV$_1$ = forced expiratory volume, first second.
COPD trials, including the assessment of pharmaceutical interventions, nasal positive pressure ventilation, and respiratory rehabilitation.

Chronic Respiratory Questionnaire

Perhaps the most popular disease-specific QOL questionnaire for use in the COPD population is the Chronic Respiratory Questionnaire (CRQ),\textsuperscript{20} also referred to as the Chronic Respiratory Disease Questionnaire (Table 1.10). The CRQ is a 20-item self-report questionnaire. It takes approximately 30 minutes to complete and is interviewer-administered. Domains are dyspnea, fatigue, emotional function and mastery. The CRQ differs from other questionnaires in two ways. First, respondents rate their dyspnea based on the performance of activities \textit{that they have selected}. This self-selection of activities have raised the criticism that the dyspnea domain cannot be compared between subjects, as each subject is responding to a different question.\textsuperscript{85} As the other three domains have standardized questions, comparison between subjects is possible. The second major difference between the CRQ and other questionnaires is that the post-intervention questionnaire asks the respondent to answer based on their previous answer in the pre-intervention questionnaire. For example, if the respondent had indicated he/she had experienced moderate shortness of breath performing an activity, the next administration would inform the respondent of their previous answer - moderate shortness of breath -- and then ask how his/her shortness of breath currently compared. This method of gaining post-intervention scores has led critics to claim this type of questionnaire has an inherent bias.\textsuperscript{86} Guyatt et al,\textsuperscript{86} creators of the CRQ, responded to this criticism by conducting a randomized control trial in which subjects...
either were informed or not informed of their previous response. Guyatt et al concluded that the informed response improves the validity of the questionnaire, and allows respondents to answer questions in a consistent fashion.

Several studies have used the CRQ, reporting reliability, validity, responsiveness, and also calculations for the clinically significant important difference (Table 1.11). The CRQ has also been used in experimental studies, such as examining respiratory rehabilitation, theophylline treatment and withdrawal and respiratory muscle training. Although widely used, one potential failing of the questionnaire is its lack of questions regarding physical ability. Activity-related questions assess dyspnea only; yet dyspnea is only one symptom which limits activity in this population. Jones and Killian noted that on symptom-limited exercise tests, one-third of COPD patients are limited by lower-extremity fatigue and weakness, and another third are limited by a combination of leg weakness and dyspnea. The CRQ may be unable to pick up decreases in physical function related to muscle fatigue and weakness if the individual did not experience dyspnea with that activity as well. Regardless of these limitations, however, the CRQ does appear to be an effective tool for QOL assessment in the COPD population.

Other Disease-Specific Questionnaires for COPD

Other disease-specific questionnaires for COPD have been developed. Some of these are: the Pulmonary Functional Status and Dyspnea Questionnaire, the Pulmonary Functional Status Questionnaire, and the Quality-of-Life for Respiratory Illness Questionnaire. At present, these questionnaires have been reported
infrequently in health care literature. Future studies may show the relative validity, reliability and responsiveness characteristics for these questionnaires.

EXPANDING QUALITY OF LIFE ASSESSMENT IN HEALTH CARE

One purpose of quantitative research is to provide a statistical comparison of two or more groups of patients or interventions\(^94\) in order to generate knowledge that may be generalizable to similar patient populations. In so doing, quantitative research has been described as following a rationalistic paradigm or approach.\(^95\) This approach focuses on reductionism as a means of explaining reality – one may understand the whole by understanding the parts. By testing hypotheses and developing theories, known as the deductive approach, knowledge is ‘discovered’.\(^95\) Quantitative research is an extremely effective way of determining the physiologic benefits of therapeutic interventions. Results of quantitative research are often generalized to populations with similar characteristics of the study sample.

Unfortunately, there are limitations to using quantitative methods for certain research questions. Quantitative research results may not provide comprehensive information on whether or not an intervention was implemented as planned, or how the subjects perceived the intervention.\(^94\) Information on the context of change in an individual is often not detected, so the process of change may be undetermined. Attempting to reduce an abstract concept such as QOL to a quantifiable number may make such measurement meaningless to both the individual patient and practitioner. How does a score of 20, for example, describe the experience of QOL in any one
individual? Unique aspects of QOL may be lost when assessed with quantitative methods.

An alternative methodology, qualitative research, may provide information on the individual experiences and on the context of change. Qualitative research employs methods such as observation, interviews, focus groups, and diaries to gain information on beliefs, feelings and meanings of reality. Qualitative research focuses on description and interpretation in an effort to gain awareness and understanding of a phenomenon within the contextual setting of the individual. It is not meant to provide generalizable data, which may limit the application of the results to populations as a whole.

Understanding changes that occur after a multicomponent intervention can be challenging. Using only quantitative methods may limit the information on the process of change, or may not capture the features characteristic of the subsample being studied, whereas a qualitative study may not provide answers that can be applied to individuals beyond the study sample. To address this limitation, some health care researchers have advocated for the use of both methodologies within the same study. This approach has been referred to as mixed-methods, or triangulation research. Although data is collected from multiple sources such as standardized questionnaires, physiological measures, patient charts, interview or observations, it is similar in focus.

There are several potential uses for mixed-methods research. They include:
1) the enhancement of the description of a process under study; 2) the identification of a chronology of events; 3) the provision of evidence for internal validity; and 4) the
corroboration or validation of study findings.\textsuperscript{97} Duffy\textsuperscript{96} corroborates: "...qualitative and quantitative methods can work iteratively to derive a more complete understanding of the phenomenon under study; and neither necessarily takes precedence over the other."

By using mixed-methods, researchers may determine the benefits of an intervention that are not only generalizable to the population but are also descriptive of the individual experience.

There are limitations to mixed-methods research. Researchers must be proficient in both research types in order to reduce error and inaccurate conclusions. Time and financial resources may be strained due to the complex nature of these studies.\textsuperscript{95,98} Analysis and integration of the data can present many difficulties,\textsuperscript{98,99} including correlating different units of analysis, the relative weighing of different types of data, and dealing with divergent results between numerical and linguistic data.\textsuperscript{96} There is pressure on the analyst to reconcile the conflicts, yet there is little advice to researchers on how to best integrate the data. Clearly defining the purpose of the study and the relative objectives of each methodology may aid analysis and prevent inaccurate conclusions. In spite of these limitations, mixed-methods research may enhance the validity of any study seeking to understand intangible concepts, such as QOL. In addition, many therapeutic interventions are complex, so it may be difficult to determine the processes by which QOL is impacted. Mixed-methods research may provide some insight on those processes, by assessing not only the magnitude of the change in the sample (via quantitative methods) but also how individuals feel the change occurred (via qualitative methods).

Studies utilizing mixed-methods are now undertaken in the scientific
community, particularly in those studies that encompass program evaluation. One study combined epidemiological data, open-ended interviews, and ethnographic field notes in its assessment of an AIDS prevention program for those engaged in the sex industry. The researchers felt using only one methodology would not provide "a comprehensive assessment of how to reach sex workers with effective AIDS risk reduction messages..." Hilton combined interviews and questionnaires in an analysis of family communication patterns when coping with breast cancer. Mixed method design have also been used in the assessment of worksite smoking policy, rural health service delivery, sleep concerns in older adults, nurse-given wellness care, and other social programs. In most instances, mixed-methods designs have been implemented when the intervention or phenomenon is dynamic, multidimensional, complex, or difficult to isolate.

Respiratory rehabilitation is an intervention for individuals with COPD specifically designed to improve QOL, and may be amenable to mixed-methods research. It combines exercise training, education and behavior modification to help reduce symptoms and enhance patient's ability to cope with the disease. The next section will describe respiratory rehabilitation and its potential impact on QOL.

RESPIRATORY REHABILITATION: A QUALITY OF LIFE INTERVENTION

Definition of Respiratory Rehabilitation

Exercise and education programs for individuals with chronic lung disease have been a part of standard care for several decades, but only more recently has the practice
been subject to scientific scrutiny and standardization. Now commonly referred to as respiratory rehabilitation (or ‘pulmonary rehabilitation’), it employs a variety of modalities to treat the chronic lung patient. The American Thoracic Society recognized the value of respiratory rehabilitation in 1981 when it published a position paper on the subject and provided the following definition:

(Respiratory) rehabilitation may be defined as an art of medical practice wherein an individually tailored multidisciplinary programme is formulated which through accurate diagnosis, emotional support and education, stabilises or reverses both physio- and psychopathology of pulmonary diseases and attempts to return the patient to the highest possible functional capacity allowed by his pulmonary handicap and overall life situation.\(^{107}\)

A more recent definition created by the National Institute for Health on Pulmonary Rehabilitation Research\(^ {108} \) refined the definition to reflect the increasing scientific basis of respiratory rehabilitation, as opposed to the ‘art’ of medical practice:

(Respiratory) rehabilitation is a multidimensional continuum of services directed to persons with pulmonary diseases and their families, usually by an interdisciplinary team of specialists, with the goal of achieving and maintaining the individual’s maximum level of independence and functioning in the community.

Components of Respiratory Rehabilitation

Respiratory rehabilitation programs have both exercise and education components. The main goal of rehabilitation is to reverse the downward spiral of the individual’s functional abilities, and in doing so may improve QOL, physical activity tolerance, medication usage, and health care utilization.\(^{109,110} \) A variety of exercise
modalities are used to improve activity tolerance (Table 1.12). Most respiratory rehabilitation programs offer exercise sessions three times per week, with each session lasting an hour or more. Aerobic exercise prescriptions are commonly derived using dyspnea levels measured during exercise tests. Individuals are encouraged to exercise to some percentage of the peak dyspnea level measured during the test.

In addition to exercise, there are several educational, behavioral, and psychosocial components to respiratory rehabilitation (Table 1.13). A multidisciplinary team involving physical therapists, respiratory therapists, occupational therapists, respiratory nurses, respirologists, pharmacists, and dietitians is utilized to provide information and training.

Benefits of Respiratory Rehabilitation

The benefits of exercise in respiratory rehabilitation have been extensively discussed in the literature, with improvements noted in muscle strength, physical endurance, and reduced ventilation, lactic acidosis and heart rate levels. How improvements in exercise affect QOL in individuals with COPD is not completely understood, but it may be due in part to decreases in the perception of dyspnea and/or improved ability to perform ADLs.

Although considered a necessary part of respiratory rehabilitation, the actual benefits attributed to the various educational, behavioral, and psychosocial components have not been clarified. This may be due in part to the difficulty in measuring psychological and behavioral characteristics as well as the interactive and cumulative effect of many of these components. Studies evaluating programs with behavioral,
Table 1.12. Exercise Modalities Used in Respiratory Rehabilitation

<table>
<thead>
<tr>
<th>Aerobic (endurance training)</th>
<th>Cycle ergometry</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Walking</td>
</tr>
<tr>
<td></td>
<td>Treadmill exercise</td>
</tr>
<tr>
<td></td>
<td>Unsupported arm exercises, with or without low resistance</td>
</tr>
<tr>
<td>Strength &amp; Flexibility</td>
<td>Weight training</td>
</tr>
<tr>
<td></td>
<td>Stretching exercises</td>
</tr>
<tr>
<td></td>
<td>Ventilatory muscle training</td>
</tr>
<tr>
<td>Other</td>
<td>Breathing exercises</td>
</tr>
<tr>
<td></td>
<td>for relaxation</td>
</tr>
<tr>
<td></td>
<td>to reduce airflow limitation</td>
</tr>
<tr>
<td></td>
<td>Tai chi</td>
</tr>
</tbody>
</table>

Table 1.13. Educational, Behavioral, & Psychosocial Components of Respiratory Rehabilitation

<table>
<thead>
<tr>
<th>Educational Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD Pathophysiology and Anatomy</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>Community Resources</td>
</tr>
<tr>
<td>Travel Issues</td>
</tr>
<tr>
<td>Oxygen Therapy</td>
</tr>
<tr>
<td>Nutrition</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavioral &amp; Psychosocial Components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking Cessation</td>
</tr>
<tr>
<td>Stress Reduction</td>
</tr>
<tr>
<td>Energy Conservation</td>
</tr>
<tr>
<td>Coping Techniques</td>
</tr>
<tr>
<td>Airway Clearance</td>
</tr>
<tr>
<td>Counselling</td>
</tr>
</tbody>
</table>
education, or psychosocial interventions provided in the absence of exercise training have found little benefit in terms of coping behaviors, psychosocial functioning or stress reduction,\textsuperscript{112} whereas psychological outcomes from multicomponent programs have shown mixed results – with one study\textsuperscript{119} reporting reduced anxiety and depression while others did not.\textsuperscript{117,120} Why a consistent result has not been found is not clear, but it may partially be due to the fact that the prevalence of anxiety and depression in COPD has been difficult to determine, and other psychosocial disorders including social isolation and reduced self-esteem may not be accurately assessed by anxiety and depression scales.

**Quality of Life Measurement and Respiratory Rehabilitation**

Respiratory rehabilitation is considered to improve QOL in individual with COPD, according to studies using generic and disease-specific questionnaires.\textsuperscript{88,89,113} To date, no study has utilized a mixed-methods approach, incorporating both standardized questionnaires and semi-structured personal interviews. Inclusion of qualitative data in a quantitative study may elicit information on the relative strengths of the various components in respiratory rehabilitation in terms of their ability to impact QOL.

**OVERALL OBJECTIVES**

The purpose of this chapter was to review definitions and issues contributing to the assessment on QOL in the COPD population. An overview of COPD revealed how
QOL may be affected in this population, and several QOL questionnaires used in the COPD population were presented. Yet several questions surround the use of QOL questionnaires in the COPD population. Do these questionnaires accurately assess QOL and are they sensitive to change in QOL after a therapeutic intervention? Are there aspects of QOL changes which occur that are not captured by these questionnaires?

One method of determining the relative completeness of a questionnaire in assessing QOL is to combine questionnaire utilization with qualitative methods. Qualitative methods used in this context could provide an exploratory function by providing additional information on QOL in COPD.

A therapeutic intervention designed to improve QOL in COPD is respiratory rehabilitation. By incorporating various educational, exercise, behavioral and psychosocial components into one comprehensive program, respiratory rehabilitation has been demonstrated to improve QOL as measured by questionnaires. How these changes in QOL occur is not known, as well as the overall ability of individual generic or disease-specific questionnaires to comprehensively assess QOL. Therefore the purpose of this study is to assess the changes in QOL in individuals with COPD who have undergone respiratory rehabilitation.

The QOL questionnaires selected for this study were the SF-36, a generic questionnaire, and the CRQ, a disease-specific questionnaire. The combination of both a generic and a disease-specific questionnaire within the same study has been recommended.\textsuperscript{18} The SF-36 was selected for two reasons. First, it is a short questionnaire that takes only 10 minutes to complete. Second, it has demonstrated
good reliability and validity for both the individual domains, and the summary scores.\textsuperscript{19,121,122} The CRQ was selected over the other COPD QOL questionnaires because it has demonstrated good validity, reliability, and responsiveness in several COPD trials. It incorporates both physical and emotional health, whereas another common COPD QOL questionnaire, the SGRQ, does not include emotional function questions. Finally, a minimally important clinical difference has been calculated for COPD patients\textsuperscript{123} allowing for the analysis of both statistical and clinical significance.

In addition to questionnaires that quantify QOL, semi-structured personal interviews were conducted in order to obtain qualitative information on the perceptions of the participants after respiratory rehabilitation. The purpose of the qualitative data was not to validate the conclusions derived from the quantitative analysis. Rather, it was used as a means of exploring the concept of QOL in COPD and the individual process of QOL change after respiratory rehabilitation. The qualitative data also assisted in identifying which components of respiratory rehabilitation were seen to have the greatest impact on QOL.

\textbf{HYPOTHESES AND RESEARCH QUESTIONS}

The following hypotheses were tested in this study: respiratory rehabilitation would improve quality of life, as measured by Physical Function and Emotional Function components of the Chronic Respiratory Questionnaire, and the Physical Summary and Mental Health Summary components of the Medical Outcomes Study Short-Form 36. These measures would not change during the Control Phase prior to
the Respiratory Rehabilitation.

In addition to the above hypotheses, the qualitative interviews were aimed at answering the following research questions: What were the perceptions of some of the participants of the respiratory rehabilitation program? and What were the changes perceived by some of the participants due to their participation in the respiratory rehabilitation program?
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Chapter 2. Quality of Life after Respiratory Rehabilitation in Individuals with Chronic Obstructive Pulmonary Disease

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a chronic, progressive, disabling disease that can have a severe impact on quality of life. Although there is no cure for COPD, there are a number of therapeutic interventions that are designed to minimize symptoms and in so doing, could have an effect on quality of life. Respiratory rehabilitation is one intervention which combines exercise, education, and behavior modification strategies in an effort to improve the fitness level and coping skills of individuals with COPD. As this intervention can help minimize the negative aspects of the disease, it likely could have a positive impact on quality of life (QOL). Previously, respiratory rehabilitation has been evaluated using mainly physiologic quantitative measures, such as exercise tolerance, oxygen consumption, and workload performance. More recently, evaluation of rehabilitation has been expanded to include subjective measures, such as dyspnea scales, and standardized QOL questionnaires.

The addition of QOL questionnaires in the evaluation of respiratory rehabilitation may broaden the scope of the evaluation and perhaps provide a more comprehensive assessment of the benefits of respiratory rehabilitation. This is because the questionnaires attempt to assess the extent of disability experienced by the individual, instead of merely the severity of impairment due to the lung disease. These questionnaires have been developed and tested on large groups of individuals. In so
doing, the selection of test items may have the best potential to represent the group but may be limited in their ability to capture the specific manner in which respiratory rehabilitation could impact an individual.

Utilizing both quantitative and qualitative methods to assess QOL changes after respiratory rehabilitation may address this limitation. The incorporation of qualitative data on the experience and benefits of respiratory rehabilitation as told by some of the participants may enhance the assessment of QOL, and provide further information on how QOL is affected in this study sample beyond that measured with the questionnaires. Therefore the purpose of this study was to determine the changes in QOL in individuals with COPD who have undergone a respiratory rehabilitation program using both quantitative and qualitative methods of assessment. The previous chapter introduced the issues surrounding QOL assessment of individuals with COPD, including the QOL questionnaires used in this population. Mixed-methods research and respiratory rehabilitation were also described. This chapter will present the methods, results and discussion of this research study.

METHODS

Sampling, Participants and Recruitment

A convenience sample of participants was recruited from two respiratory rehabilitation programs in British Columbia, Canada: Saint Mary's Hospital Respiratory Rehabilitation Program, and Ridge Meadows Hospital Respiratory Rehabilitation Program. Participants had met the admission criteria for the program (Table 2.1) and had undergone an indepth assessment (Table 2.2). Ethics approval for
Table 2.1 Admission Criteria for the Respiratory Rehabilitation Programs

<table>
<thead>
<tr>
<th>Saint Mary's Hospital</th>
<th>Ridge Meadows Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ Clinical diagnosis of chronic obstructive pulmonary disease</td>
<td>♦ Must have evidence of chronic, disabling lung disease</td>
</tr>
<tr>
<td>♦ Symptomatic chronic airflow obstruction</td>
<td>♦ Must be motivated to improve and must have quit smoking</td>
</tr>
<tr>
<td>♦ A desire to improve health status, and a commitment to attend the entire 5 week program</td>
<td>♦ Must have no uncontrolled underlying disease process</td>
</tr>
<tr>
<td>♦ Referral by a family physician or respirologist</td>
<td>♦ Must pass a stress test</td>
</tr>
<tr>
<td>♦ Past consultation with an internist or respirologist</td>
<td></td>
</tr>
</tbody>
</table>
Table 2.2 Assessment Procedures for Saint Mary’s Hospital Respiratory Rehabilitation Program and Ridge Meadows Hospital Respiratory Rehabilitation Program

<table>
<thead>
<tr>
<th>Saint Mary’s Hospital</th>
<th>Ridge Meadows Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ Specialist Consultation</td>
<td>◦ Specialist Consultation</td>
</tr>
<tr>
<td>◦ Arterial Blood Gases</td>
<td>◦ Arterial Blood Gases</td>
</tr>
<tr>
<td>◦ Pulmonary Function Tests</td>
<td>◦ Pulmonary Function Tests</td>
</tr>
<tr>
<td>◦ Walk Test with oximetry</td>
<td>◦ Walking, Treadmill, and Step Tests</td>
</tr>
<tr>
<td>◦ Blood work</td>
<td>◦ Strength Test</td>
</tr>
<tr>
<td>◦ Chest X-Rays</td>
<td>◦ Medication Delivery Assessment</td>
</tr>
<tr>
<td>◦ Resting Electrocardiogram</td>
<td>◦ Dyspnea Assessment</td>
</tr>
<tr>
<td>◦ Patient Interview</td>
<td>◦ Patient Interview</td>
</tr>
</tbody>
</table>
this study was obtained from the University of British Columbia, Saint Mary’s Hospital, and Ridge Meadows Hospital (Appendix B).

After participants were admitted to the respiratory rehabilitation program they were then assessed to determine their suitability for the study. Inclusion and exclusion criteria are listed in Table 2.3. The program staff did the initial assessment determining the suitability of each program participant. If a participant was deemed suitable, the program staff questioned the participant regarding his or her interest in participating in the study, and the researcher was then notified. The researcher confirmed the participant’s suitability and contacted the participant, in order to arrange the first testing session and to obtain informed consent (Appendix B).

Study Protocol

Upon giving informed consent, each participant underwent the first testing session, known as the Pre-Control test. Each participant completed the two QOL questionnaires and underwent a simple spirometric test. The purpose of the spirometric test was to ensure the stability of the participant’s airflow obstruction over time. The order of the questionnaires and spirometric testing during each session was randomly determined at each session. The participant then waited for five weeks, called the Control Phase, during which time he or she continued with the usual medical management. At the end of the five-week Control Phase, the participant then repeated the questionnaire testing and the spirometric testing, designated as the Pre-Rehabilitation Test. The participant then entered the five-week Rehabilitation Phase at either Saint Mary’s Hospital or Ridge Meadows Hospital (see description of the
Table 2.3 Study Inclusion and Exclusion Criteria

**Inclusion Criteria**

1. Diagnosis of COPD; specifically chronic bronchitis, emphysema, or bronchiectasis.
2. Mild to severe COPD, as determined by an FEV₁ less than or equal to 70% predicted.
3. Willingness to participate in the Control Phase of the Study, and wait 5 weeks before entering the Respiratory Rehabilitation program.
4. Willingness to participate in the Respiratory Rehabilitation Phase.
5. An ability to read and understand the QOL questionnaires.
6. An ability to undergo spirometric testing.

**Exclusion Criteria**

1. Diagnosis of chronic asthma in the absence of chronic bronchitis and emphysema. Patients with chronic asthma were excluded due to the fact that chronic asthma is a highly variable condition with unpredictable symptoms. This lack of disease stability would make it difficult to determine the relative impact of respiratory rehabilitation versus disease variability on QOL.
2. Lack of stability in pulmonary condition, defined as having a respiratory infection requiring antibiotics within six weeks of study admission, or having a hospital admission within 3 months of study admission.
3. Attendance at a respiratory rehabilitation program within the last 3 years.
4. Severe or unstable co-morbid condition, including any musculoskeletal, cardiovascular, gastrointestinal, or psychiatric condition.
5. Incidence of respiratory infection or hospitalization during the 10-week course of the study.

COPD = Chronic obstructive pulmonary disease; FEV₁ = Forced expiratory volume, first second. QOL = Quality of life
respiratory rehabilitation intervention in the next session of Methods). At the end of the Rehabilitation Phase, the participant then completed the last testing session, designated the Post-Rehabilitation Test (see Figure 2.1). All testing was performed by the researcher.

After the Post-Rehabilitation Test, participants were asked if they would be interested in participating in a personal interview with the researcher. Each member of this subsample was then interviewed in his or her own home. Seven people (five women, two men) participated in the interviews (Table 2.4). These interviews were semi-structured in nature and recorded on audiotape. The interviews were later transcribed.

Description of Respiratory Rehabilitation Program

The Saint Mary's Hospital Respiratory Rehabilitation program, located in New Westminster, British Columbia has been in operation since 1979. The current staff members have been a part of the program for a minimum of eight years, and consist of two respiratory nurses and one physiotherapist. The program has a respirologist as the medical director, and employs a full-time office manager. In addition to operating the Rehabilitation program, the staff is involved with community events, research studies, and local COPD support groups. The program staff has developed a program package, available for sale to any facility that wishes to start their own respiratory rehabilitation program. This package comes complete with education manuals, an exercise video, policy and procedure manuals and assessment forms. They have developed a five-week program with participants attending on a thrice-weekly basis. Each session lasts
Figure 2.1. Study Protocol.
Participants began with the Pre-Control Test, then waited through the 5 week Control Phase. They then underwent the Pre-Rehab Testing, followed by the 5 week Respiratory Rehabilitation Phase. The last testing occurred at the end of the Respiratory Rehabilitation. Within two weeks of the last testing, a subsample of participants participated in the semi-structured interview. CRQ = Chronic Respiratory Questionnaire; SF-36 = Medical Outcomes Study Short Form 36
Table 2.4 Characteristics of Participants for Personal Interviews

<table>
<thead>
<tr>
<th>Subject</th>
<th>Age</th>
<th>Gender</th>
<th>Disease Severity</th>
<th>Oxygen Use</th>
<th>Lives Alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>86</td>
<td>F</td>
<td>Moderate</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>74</td>
<td>F</td>
<td>Moderately Severe</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>16</td>
<td>74</td>
<td>M</td>
<td>Moderately Severe</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>17</td>
<td>68</td>
<td>M</td>
<td>Severe</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>25</td>
<td>71</td>
<td>F</td>
<td>Very Severe</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>33</td>
<td>62</td>
<td>F</td>
<td>Moderately Severe</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>42</td>
<td>63</td>
<td>F</td>
<td>Very Severe</td>
<td>About to</td>
<td>No</td>
</tr>
</tbody>
</table>
approximately 2.5 hours, with exercise and education provided at each session. The program enrolls sixteen participants for each session, and the exercise sessions are monitored by two of the three health professionals on staff.

The Ridge Meadows Respiratory Rehabilitation program is located in Maple Ridge, British Columbia. This program is based on the Saint Mary’s Hospital Program, with the exception that the program lasts for eight weeks, and incorporates strength training in their exercise sessions. This program is run by two respiratory therapists and has a respirologist as the medical director. Any subject attending this program underwent their Post-Rehabilitation Test after completing five weeks of the program, in order to keep the timing of the test and the content of the respiratory rehabilitation received similar to those participants who attended the Saint Mary’s Respiratory Rehabilitation program.

Each participant participated in both the exercise and education sessions of the rehabilitation program (See Appendix C for information on the content of the rehabilitation programs).

Assessment of Outcome

QOL Questionnaires

The two QOL measures used in this study were the Medical Outcomes Study Short Form 36 (SF-36)\(^7\) – Acute Version, and the Chronic Respiratory Questionnaire (CRQ)\(^8\) (Appendix A).

The SF-36 is a generic questionnaire that can be either interviewer-administered in person or over the telephone, or self-administered. The self-
administered questionnaire was used for this study. It has 36 items divided into eight categories (Table 2.5). Questions ask the individual to rate certain aspects of their overall health, their ability to perform activities of daily living, their emotional status, levels of pain, and their perception of their health compared to others around them.

Items are tabulated and weighted. These raw scores are changed to a transformed score which can then be compared with norms derived from the Medical Outcomes Study 1990 National Survey of Functional Health Status. In addition to the scores for the eight individual categories, a Physical Summary Component score and a Mental Health Component Summary score can be calculated (Table 2.5). These scores are derived from the eight domains, and using a z-score transformation, yield values that can be compared to norms for the general U.S. population. Ware et al concluded that the reduction of eight categorical scores into two summary scores can be achieved without a substantial loss of information.

Several studies have examined the reliability and validity of the SF-36. These studies have been presented in Chapter One. In short, McHorney et al concluded that the SF-36 has met the minimum required standards for reliability across all categories. Good validity of the SF-36 has also been determined across a variety of patient groups, and three studies involving individuals with chronic lung disease concluded the SF-36 is a valid, discriminative measure of QOL in this population.

The second QOL questionnaire used in this study is the Chronic Respiratory Questionnaire (also known as the Chronic Respiratory Disease Questionnaire), developed by Gordon Guyatt et al of McMaster University. The reliability and validity of this questionnaire has been established. This interviewer-administered,
Table 2.5. Categories of the SF-36 and the CRQ

<table>
<thead>
<tr>
<th>SF-36</th>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Domain</strong></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
<td></td>
</tr>
<tr>
<td>Role – Physical</td>
<td></td>
</tr>
<tr>
<td>Bodily Pain</td>
<td></td>
</tr>
<tr>
<td>General Health</td>
<td></td>
</tr>
<tr>
<td>Vitality</td>
<td></td>
</tr>
<tr>
<td>Social Functioning</td>
<td></td>
</tr>
<tr>
<td>Role – Emotional</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td></td>
</tr>
<tr>
<td><strong>Component</strong></td>
<td></td>
</tr>
<tr>
<td>Physical Summary</td>
<td></td>
</tr>
<tr>
<td>Mental Health Summary</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CRQ</th>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Domain</strong></td>
<td></td>
</tr>
<tr>
<td>Dyspnea</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td>Emotional Function</td>
<td></td>
</tr>
<tr>
<td>Mastery</td>
<td></td>
</tr>
<tr>
<td><strong>Component</strong></td>
<td></td>
</tr>
<tr>
<td>Physical Function</td>
<td></td>
</tr>
<tr>
<td>Emotional Function</td>
<td></td>
</tr>
</tbody>
</table>

SF-36 = Short Form 36; CRQ = Chronic Respiratory Questionnaire
The disease-specific questionnaire has 20 questions covering four domains: Dyspnea; Fatigue; Emotional Function; and Mastery (Table 2.5). The Mastery domain refers to a sense of control over the disease process. Each question has a seven point Likert scale, with higher scores reflecting better physical or emotional well-being. To score a particular domain, the answers for each question in the domain are added together and then divided by the number of questions within the domain. The score for each domain then ranges between one (1) and seven (7). Scores from the Dyspnea domain and the Fatigue domain can then be combined to form the Physical Function component, and the Emotional Function and the Mastery domains can be combined to make the Emotional Function component (Table 2.5) as per Guyatt et al.\textsuperscript{18} The Physical Function Component or the Emotional Function Component is derived by taking the average of the two domains that make up each component. In this way, these components are also expressed as a number between one and seven, with higher scores representing greater QOL.

Another possible way of expressing these scores is to calculate the score as a percentage of the total possible score. The total score for each component is divided by the highest possible score for each component and multiplied by 100. This method can then allow comparison between other questionnaires that utilize a percentage scoring system. The percentage method was used for this study.

In order to gain familiarity and assess the test-retest reliability of the questionnaires, another sample of 10 individuals with COPD was recruited. The inclusion/exclusion criteria were the same, except the minimum FEV\textsubscript{1} value was < 60% of predicted rather than ≤ 70% of predicted. The sample was administered three QOL
questionnaires, the Sickness Impact Profile, the CRQ, and the Short-Form 36. The spirometric assessment was also done. The testing was then repeated in two weeks. The test-retest reliability data, as analysed using an Interclass Coefficient (ICC, [1,3]), showed a range of r=0.81-0.95, for the different components of the SIP, the SF-36, and the CRQ (Table 2.6) These are considered excellent correlations according to the criteria established by Shrout and Fleiss (r>0.75 = excellent correlation). The test-retest reliability raw data is presented in Appendix F.

**Spirometric Testing**

Each participant underwent spirometric testing at each testing session. A Microplus (VitalAire, Edmonton, Alberta) handheld spirometer was used. Each participant wore noseplugs unless they were on oxygen via nasal prongs. The participant was asked to exhale in a relaxed fashion, then inhale until they felt they could get no more air into their lungs. The participant then placed his mouth over the mouthpiece on the handheld spirometer, and was instructed to blow out as hard and as fast as he or she could, and to keep blowing out into the spirometer until they felt they had no more air left in their lungs. The participant was then given a rest period. This maneuver was repeated three times, with two measurements recorded. The first measurement was the forced expiratory volume in the first second (FEV$_1$) and the second measurement recorded was the forced vital capacity (FVC). The FEV$_1$ is an indication of disease severity in COPD. The FVC reflects the total amount of air the individual can expel from their lungs and also tends to be reduced in individuals with COPD. The participant was asked to repeat the maneuver a minimum of three times, as
Table 2.6. Test-Retest Reliability of Three Quality of Life Questionnaires

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Component</th>
<th>Interclass Correlation (1,3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIP</td>
<td>Psychological</td>
<td>0.95</td>
</tr>
<tr>
<td></td>
<td>Physical</td>
<td>0.86</td>
</tr>
<tr>
<td>SF-36</td>
<td>Mental Health Summary</td>
<td>0.91</td>
</tr>
<tr>
<td></td>
<td>Physical Summary</td>
<td>0.81</td>
</tr>
<tr>
<td>CRQ</td>
<td>Emotional Function</td>
<td>0.95</td>
</tr>
<tr>
<td></td>
<td>Physical Function</td>
<td>0.95</td>
</tr>
</tbody>
</table>

SIP=Sickness Impact Profile; SF-36=Medical Outcomes Study Short Form 36; CRQ=Chronic Respiratory Questionnaire
per American Thoracic Society guidelines for spirometric measurement. The participant was required to give three maneuvers with the FEV₁ scores within five percent of one another, and continued to repeat the maneuvers until this was obtained or until the participant refused to continue. Of the three FEV₁ scores within five percent, the highest value was recorded.

**Perceptions of Clients About Program and Outcomes Through Qualitative Interviews**

After the final testing session, participants were asked if they would be willing to participate in the interview. An attempt was made to recruit participants for interviewing who represented the whole sample in terms of age, gender, and disease severity, known as purposive sampling. Each interview was conducted in the participant’s home, and occurred within two weeks of the Post-Rehabilitation Test. All interviews were conducted by the same researcher. Participants were informed that the interview would be audiotaped and transcribed verbatim and they were invited to review the transcription of the interview if they wished; however, no participant requested to view the transcription. The interviewer followed a semi-structured interview format, with three main trigger questions that focused on:

1. participants’ perception of the program and the changes they perceived as being due to the program,
2. the strengths and weaknesses of the program,
3. the recommendations for improving the program.

The participants were free to speak on any aspect of the respiratory rehabilitation program, but the researcher did have a list of questions in order to request information related to the specific topics (Appendix D). These questions asked the
participant about specific aspects of the rehabilitation program and were used if the
participant required a little prodding. Any information identifying the participant, the
program staff, or any other health care professional was deleted from the transcript.
The staff at the rehabilitation programs was not informed of whom had agreed to do the
personal interviews, in order to enable each participant to speak about their respective
program in a confidential manner.

One difficulty with recruiting participants for the interviews was the potential
underrepresentation of any individuals who might have criticisms of the program.
Enthusiastic participants may have self-selected themselves for the interview, grateful
participants may have felt apprehension about voicing any criticism, and if anyone
disliked the program they may not have agreed to be interviewed. Any potential
problems with participants providing the answers they think the researcher wants to
hear, or the additional problem of the participants inadvertently changing their behavior
because they knew they were being studied (the Hawthorne effect) was minimized in
this study. The researcher maintained as much distance from the program as possible.
For example, the researcher was not involved in the program delivery and made
attempts to avoid the program when the participants might be in attendance. Further
measures taken to ensure the participants were comfortable in disclosing information
included testing in the participants' homes, when possible, and assuring participants of
their confidentiality.
Data Analysis

Statistical Analysis of Quantitative Data

The demographics of the sample, including age, gender, disease severity, and smoking history were described using sample group means, ranges and standard deviations. The differences between the Pre-Control Test, the Pre-Rehabilitation Test, and the Post-Rehabilitation Test scores of the CRQ Physical Function component, the CRQ Emotional Function component, the SF-36 Physical Summary component, and the SF-36 Mental Health Summary component were studied with a repeated measures univariate ANOVA (SYSTAT, Systat Intelligent Software, Inc; Evanston, Ill.). An alpha level $< 0.01$ was determined by using a Bonferroni adjustment for multiple comparisons, due to the number of comparisons being made (Appendix E). Post hoc comparisons were made with the Tukey test.

Qualitative Analysis

Content analysis of the interview data was done in order to determine the perceptions the participants had of the program and to identify changes they had seen in themselves likely due to their participation in the program. After transcription, each interview was coded. Initially, the three main trigger questions were used to code the data, i.e. their experience in the program and changes noted due to the program, their views of the program including strengths and weaknesses, and any recommendations they might have. Following this initial process, a more thorough analysis of the data was conducted which identified major themes and their components. Guidelines for coding and analysis were provided by several resources.
RESULTS

Characteristics of the Study Participants

Participant recruitment began in January 1997 and continued until December 1997, with the last participant completing the study in February 1998. During the recruitment period, 41 participants were deemed eligible for the study and agreed to participate. Of these, twelve dropped out for a variety of reasons (Table 2.7). The characteristics of the 29 who completed the program are presented in Table 2.8. The raw data for each participant is presented in Table 2.9. The grouped frequencies in terms of age, disease severity and smoking history are presented in Table 2.10. The mean FEV₁ for the sample was 43%, which represents a sample with severe lung disease. All participants recruited for this study were white. Of the 29 recruited, 28 were from Saint Mary’s Hospital Respiratory Rehabilitation Program.

Quantitative Data Results

Questionnaire Data

The mean scores for the CRQ and the SF-36 are shown in Figure 2.2 and the individual scores are presented in Tables 2.11 and 2.12, respectively. The respiratory rehabilitation programs improved QOL as demonstrated by improved scores on three of the four questionnaire components analyzed for the CRQ and the SF-36. For the CRQ, Physical Function improved 22% (p=0.000) and Emotional Function improved 10% (p=0.000) after respiratory rehabilitation. In addition to a statistically significant change, both of these changes represented clinically significant changes as defined by Jaeschke et al. In our study, we found a raw score increase of 7.3 for the Physical
Table 2.7 Reasons for Drop-out of the Study

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Reason for Dropout</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Became sick</td>
</tr>
<tr>
<td>6</td>
<td>Became sick</td>
</tr>
<tr>
<td>7</td>
<td>Became sick</td>
</tr>
<tr>
<td>15</td>
<td>Refused to continue with study</td>
</tr>
<tr>
<td>21</td>
<td>Daughter became ill</td>
</tr>
<tr>
<td>27</td>
<td>Decided to enroll in later program</td>
</tr>
<tr>
<td>28</td>
<td>Became sick</td>
</tr>
<tr>
<td>29</td>
<td>Other unstable health problems</td>
</tr>
<tr>
<td>31</td>
<td>Changed mind about rehabilitation program</td>
</tr>
<tr>
<td>36</td>
<td>Became sick</td>
</tr>
<tr>
<td>38</td>
<td>Other unstable health problems</td>
</tr>
<tr>
<td>41</td>
<td>Husband became sick</td>
</tr>
</tbody>
</table>
Table 2.8 Characteristics of the Study Participants (N = 29)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean and (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>65% female</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>69 (8.6)</td>
<td>53 – 92</td>
</tr>
<tr>
<td>FEV₁ (litres)</td>
<td>0.95 (0.35)</td>
<td>0.55 – 1.98</td>
</tr>
<tr>
<td>FEV₁ (% predicted)</td>
<td>43% (14)</td>
<td>23-69</td>
</tr>
<tr>
<td>FVC (litres)</td>
<td>2.18 (0.75)</td>
<td>1.34-3.84</td>
</tr>
<tr>
<td>FVC (% predicted)</td>
<td>71% (20)</td>
<td>45-130</td>
</tr>
<tr>
<td>Smoking pack years</td>
<td>37 (21)</td>
<td>0 – 80</td>
</tr>
</tbody>
</table>

FEV₁ = forced expiratory volume, first second; FVC = forced vital capacity
Table 2.9 Characteristics of Individual Study Participants

<table>
<thead>
<tr>
<th>Number</th>
<th>M/F</th>
<th>Age</th>
<th>FEV₁ (% predicted)</th>
<th>Disease Severity</th>
<th>Smoking (pack years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>86</td>
<td>62</td>
<td>Moderate</td>
<td>40</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>73</td>
<td>69</td>
<td>Moderate</td>
<td>15</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>74</td>
<td>51</td>
<td>Moderate/severe</td>
<td>35</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>57</td>
<td>32</td>
<td>Very severe</td>
<td>70</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>64</td>
<td>47</td>
<td>Severe</td>
<td>60</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>68</td>
<td>37</td>
<td>Severe</td>
<td>40</td>
</tr>
<tr>
<td>11</td>
<td>F</td>
<td>79</td>
<td>42</td>
<td>Severe</td>
<td>17</td>
</tr>
<tr>
<td>12</td>
<td>F</td>
<td>75</td>
<td>68</td>
<td>Moderate</td>
<td>0</td>
</tr>
<tr>
<td>13</td>
<td>F</td>
<td>56</td>
<td>26</td>
<td>Very severe</td>
<td>9</td>
</tr>
<tr>
<td>14</td>
<td>F</td>
<td>54</td>
<td>40</td>
<td>Moderate/severe</td>
<td>37</td>
</tr>
<tr>
<td>16</td>
<td>M</td>
<td>74</td>
<td>56</td>
<td>Moderate/severe</td>
<td>12.5</td>
</tr>
<tr>
<td>17</td>
<td>M</td>
<td>68</td>
<td>42</td>
<td>Severe</td>
<td>70</td>
</tr>
<tr>
<td>18</td>
<td>F</td>
<td>66</td>
<td>27</td>
<td>Very severe</td>
<td>40</td>
</tr>
<tr>
<td>19</td>
<td>F</td>
<td>76</td>
<td>44</td>
<td>Severe</td>
<td>40</td>
</tr>
<tr>
<td>20</td>
<td>F</td>
<td>66</td>
<td>36</td>
<td>Severe</td>
<td>42</td>
</tr>
<tr>
<td>22</td>
<td>M</td>
<td>68</td>
<td>67</td>
<td>Moderate</td>
<td>40</td>
</tr>
<tr>
<td>23</td>
<td>M</td>
<td>92</td>
<td>50</td>
<td>Moderate/severe</td>
<td>0</td>
</tr>
<tr>
<td>24</td>
<td>M</td>
<td>68</td>
<td>27</td>
<td>Very severe</td>
<td>45</td>
</tr>
<tr>
<td>25</td>
<td>F</td>
<td>71</td>
<td>26</td>
<td>Very severe</td>
<td>50</td>
</tr>
<tr>
<td>26</td>
<td>M</td>
<td>63</td>
<td>26</td>
<td>Very severe</td>
<td>80</td>
</tr>
<tr>
<td>30</td>
<td>F</td>
<td>68</td>
<td>45</td>
<td>Severe</td>
<td>40</td>
</tr>
<tr>
<td>33</td>
<td>F</td>
<td>62</td>
<td>57</td>
<td>Moderate/severe</td>
<td>25</td>
</tr>
<tr>
<td>34</td>
<td>F</td>
<td>65</td>
<td>37</td>
<td>Severe</td>
<td>49</td>
</tr>
<tr>
<td>35</td>
<td>M</td>
<td>67</td>
<td>55</td>
<td>Moderate/severe</td>
<td>50</td>
</tr>
<tr>
<td>37</td>
<td>F</td>
<td>61</td>
<td>36</td>
<td>Severe</td>
<td>45</td>
</tr>
<tr>
<td>39</td>
<td>M</td>
<td>76</td>
<td>28</td>
<td>Very severe</td>
<td>40</td>
</tr>
<tr>
<td>40</td>
<td>M</td>
<td>76</td>
<td>43</td>
<td>Severe</td>
<td>0</td>
</tr>
<tr>
<td>42</td>
<td>F</td>
<td>63</td>
<td>23</td>
<td>Very severe</td>
<td>35</td>
</tr>
<tr>
<td>44</td>
<td>F</td>
<td>79</td>
<td>44</td>
<td>Severe</td>
<td>40</td>
</tr>
</tbody>
</table>

| Mean   |       |     |                    |                  | 37                  |
| SD     |       | 8.6 | 14                 |                  | 21                  |

FEV₁ = forced expiratory volume, first second; SD = standard deviation
Table 2.10  Characteristics of Participants by Grouped Frequency

<table>
<thead>
<tr>
<th>Age (years) Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>53-62</td>
<td>5</td>
</tr>
<tr>
<td>67-72</td>
<td>13</td>
</tr>
<tr>
<td>73-82</td>
<td>9</td>
</tr>
<tr>
<td>83-92</td>
<td>2</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>FEV₁ (ATS guidelines for disease severity) Group</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69% predicted (moderate disease)</td>
<td>4</td>
</tr>
<tr>
<td>50-59% predicted (moderate-severe disease)</td>
<td>5</td>
</tr>
<tr>
<td>34-49% predicted (severe disease)</td>
<td>12</td>
</tr>
<tr>
<td>&lt;34% predicted</td>
<td>8</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Smoking History (pack years) Pack years</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20</td>
<td>7</td>
</tr>
<tr>
<td>21-40</td>
<td>12</td>
</tr>
<tr>
<td>41-60</td>
<td>7</td>
</tr>
<tr>
<td>61-80</td>
<td>3</td>
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</table>
Figure 2.2 Results of the two quality of life questionnaires at the three testing sessions. CRQ scores are shown as percentages; SF-36 scores are transformed standardized scores. * indicates significant difference between Pre- and Post-Rehab phases at p < 0.001. CRQ = Chronic Respiratory Questionnaire; SF-36 = Medical Outcomes Study Short Form 36.
Table 2.11 CRQ Individual Scores

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pre-Physical Function</th>
<th>Post-Physical Function</th>
<th>Pre-Emotional Function</th>
<th>Post-Emotional Function</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Raw</td>
<td>%</td>
<td>Raw</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>42</td>
<td>67</td>
<td>44</td>
<td>70</td>
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<tr>
<td>2</td>
<td>40</td>
<td>63</td>
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<td>3</td>
<td>36</td>
<td>57</td>
<td>36</td>
<td>57</td>
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<tr>
<td>4</td>
<td>46</td>
<td>73</td>
<td>49</td>
<td>78</td>
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<tr>
<td>11</td>
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<tr>
<td>28</td>
<td>42</td>
<td>67</td>
<td>40</td>
<td>63</td>
</tr>
</tbody>
</table>

Mean 35  55  36  57  44  69  55  71  55  71  61  79
SD  8  13  8  13  7  11  10  13  11  14  8  11

*Total possible Physical Function Raw Score = 66
**Total possible Emotional Function Raw Score = 77
% = (Raw Score/Total Possible) x 100
CRQ = Chronic Respiratory Questionnaire; SD = Standard Deviation
Italicized participant numbers = interview participants
Table 2.12  SF - 36 Individual Scores*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Physical Summary</th>
<th>Mental Health Summary</th>
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<tbody>
<tr>
<td></td>
<td>Pre-Control</td>
<td>Pre-Rehab</td>
</tr>
<tr>
<td>1</td>
<td>36</td>
<td>41</td>
</tr>
<tr>
<td>4</td>
<td>26</td>
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<td>44</td>
<td>41</td>
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</table>

<table>
<thead>
<tr>
<th>Mean</th>
<th>38</th>
<th>36</th>
<th>41</th>
<th>53</th>
<th>53</th>
<th>54</th>
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</thead>
<tbody>
<tr>
<td>SD</td>
<td>8.4</td>
<td>8.2</td>
<td>7.8</td>
<td>7.7</td>
<td>9.1</td>
<td>9.6</td>
</tr>
</tbody>
</table>

* Scores are transformed z-scores. In the general U.S. population, both the Physical Summary score and the Mental Health Summary score have a mean of 50 and a standard deviation of 10.\(^9\)

Italicized participant numbers = interview participants
Function and an increase of 6.2 in the Emotional Function categories, compared to increases of 4.5 and 5.5 respectively that are required for clinical significant improvements in the CRQ.\textsuperscript{27}

The Physical Summary score of the SF-36 increased 14\% after the Rehabilitation Phase ($p=0.001$) whereas the Mental Health Summary did not change (2\% increase, $p=0.725$). There is no available information on the calculation of the minimally important clinical difference for scores of the SF-36 for the COPD population. None of the questionnaire component scores for the CRQ and SF-36 changed during the Control Phase of the study.

The effect sizes for the CRQ Physical Function and the Emotional Function components were 0.92 and 0.59, respectively. According to Cohen,\textsuperscript{28} this corresponds to a large effect size for the CRQ Physical Function and a moderate effect size for the CRQ Emotional Function component. The effect sizes for the SF-36 Physical Summary component and the Mental Health Summary was 0.61 and 0.11, respectively. This is considered a moderate effect and a negligible effect, respectively.

\textit{Spirometric Data}

The FEV\(_1\) values (Table 2.13) were stable throughout the study, showing no significant differences between any of the three test points.

\textit{Description of the Interview Participants}

There were seven people who agreed to the personal interview at the end of the respiratory rehabilitation program. Five women and two men were interviewed (Table
<table>
<thead>
<tr>
<th>FEV₁ (litres/second)</th>
<th>Pre-Control</th>
<th>Pre-Rehabilitation</th>
<th>Post-Rehabilitation</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.93 (0.38)</td>
<td>0.93 (0.38)</td>
<td>0.90 (0.39)</td>
<td>0.32</td>
<td></td>
</tr>
</tbody>
</table>

FEV₁ = forced expiratory volume, first second; SD = standard deviation
2.4). All interview participants had attended the Saint Mary’s Hospital Respiratory Rehabilitation Program. The age ranged from 62 to 86 years (mean = 71), similar to the mean age of the entire study participants of 69. Gender was also similarly represented in both groups: 71% of interview participants versus 65% of the participants in the entire study were women. There were variations in disease severity, oxygen use and social characteristics. Disease severity ranged from moderate to very severe, based on the ATS guidelines that categorize severity from FEV₁. These severity levels did appear to reflect actual levels of ability of the participants. Both participants with ‘very severe’ disease had extreme difficulty with physical activity and were socially isolated. One of these participants was about to use home oxygen. Another participant with severe disease also used oxygen.

Qualitative Interview Results

Each interview took place in the participant’s home. The participants gave permission to be audiotaped. Interviews ranged from forty-five minutes to seventy-five minutes. All interview participants were willing to answer questions, although the questions regarding emotional, psychological, or mood changes were difficult to answer for a few of the participants. In addition, all participants had very few criticisms of the program, even when asked if there were any specific areas of the program they felt could be strengthened. With regards to information obtained, there were no obvious differences between the men and the women.

The major themes that arose from the data analysis reflected how participants came to be in the respiratory rehabilitation program, their perceptions of the program,
and what changes the participants perceived to be due to the program. Each of these
themes and their secondary themes will be described (Table 2.14)

How the Participants Came to Respiratory Rehabilitation

Participants initially talked about how they came to the respiratory rehabilitation
program. Secondary themes included how the participants obtained the referral to the
program, and what were their prior expectations and attitudes before attending the
program.

Obtaining the referral. Participants often had no prior knowledge of the
program until they heard about it from their family doctor, respirologist, or occasionally
a family friend. One participant asked his doctor for a referral:

...my own doctor, he doesn’t know anything about the
program...I had to go to (my respirologist) twice, to ask...

but most often participants were instructed by their doctors to attend:

I went to a (new doctor)...he was the one that wanted me to go
into the program first.

...My doctor...he said he knew some people who had gone
through that program, and he just couldn’t believe
the change in them.

Expectations and Attitudes. Once participants acquired the referral, they had
mixed feelings about attending the upcoming program. Some participants felt the
program was a good idea and were willing to try something that might benefit them.

...I thought...anything you can do to improve your health, you
should do it...
Table 2.14 Summary of Themes from Qualitative Data

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>How Participants Came to Respiratory Rehabilitation</th>
<th>Impressions of the Program</th>
<th>Reflecting on Changes</th>
</tr>
</thead>
</table>
| **Secondary Themes** | ◆ Obtaining the referral  
◆ Expectations and attitudes | ◆ General comments  
◆ Program staff  
◆ Program content: education  
◆ Program content: exercise  
◆ Program format | ◆ Acquiring the skills and knowledge  
◆ Gaining control and feeling more energetic  
◆ Realizing one’s potential |
Decided it’s best to do what the doctor says...I liked the idea...I’d have probably went months earlier if someone had suggested it.

One woman with very severe disease was not as hopeful, but she felt that because her doctor had suggested the program, she should go. However, she was not optimistic about the outcome:

*I am a believer in doing what you’re told...so that was why I went...(but)I went there with absolutely no hopes. Didn’t expect anything. Felt that I was going to last two sessions and then I was going to quit.*

One of the main reasons for her pessimism was that she felt her lung condition was so severe, positive changes were not possible.

*I had emphysema. What are you going to do about emphysema? It’s permanent. They’re not going to be able to do anything for me...this is the way my life is,...okay, I’m pretty well house-bound, and make the best of it. I just thought that was it.*

The other woman with very severe COPD had similar feelings, based on the feedback she received from her doctor:

"...there’s really nothing we can do about it.” That was the (doctor’s comment). It was, "...just go home, you’re lucky to have your husband...lots of guys would just up and leave you...this is your problem, just take this puffer and you go home.”

A few participants were also a bit skeptical about attending the program because of the time commitment required. Two women commented:

*I thought three times a week was a bit much...*
Three times a week, my gosh! ... I thought that was lots ... that’s interfering with my social life ... because I would have to go to class and miss what I’m doing at the (community) centres ... If I was younger I wouldn’t be that scared, but at my age, they would maybe get someone else (to fill her job as a volunteer). That’s what I’m scared of... (my volunteer work) is just as important as my breathing...

Because of her other commitments, the second woman quoted above had to be persuaded to attend:

... when I did go to see (program staff member) I didn’t know whether I wanted to (attend) or not. I might have told her ... that I didn’t think I did. And she said, “Well, I think you should.” So we kinda argued back and forth, so she finally said to me, “Well then, you come and see, and if you don’t like it, you can quit.” So she won out in the end.

Impressions of the Program

Overall, the participants felt the program was very good. There were many positive comments on the high caliber of the program and the staff, as well as other compliments on the format of the program and the content delivered. All were pleased they had taken the program:

I would have made a bigger mistake if I hadn’t of went, I’m sure of that.

I think it’s just excellent, period.

... the program is a well-rounded program ... it’s very complete ...

Many participants believed that more people should attend respiratory rehabilitation programs. The two men stated:

... if they can stand more people attending, they should be ...

... the only thing I would say that anyone with a lung disease would be foolish not to take it, if they had the opportunity...
A few participants remarked that they were accustomed to attending the program, and missed going there when it was over. Two women stated:

...I find I missed (something) after I quit (finished). I'd wake up Monday morning and think, “Gee, I'm not going to (the program).” You kinda missed it...

...the overall picture was, on the cessation of the course, “Gosh, I'm missing something”...

In addition to the general positive comments about the program, participants had many specific comments about the program staff, the format of the program, the content (in terms of the exercise and the various education topics) and the other participants.

Program Staff. The participants felt the program staff were extremely good at their jobs. Many attributed the success of the program to the high caliber of the staff in terms of professionalism, motivation, enthusiasm, and supportive behavior. Participants were also aware of the extensive experience in respiratory disease of the staff. Comments describing these specific areas are presented below.

They made you feel good when you went there...as soon as you come in...

They even told you if you...need any help or anything, they will help you...they're there for you...

The nurses let me know, "You can do it! Don't give up, you can do it!"

They spent a lot of work for the notes, the preparation...The instructors they had were top-rate...I don't think they could be any better. 'Cause they have many years at it and they are quite experienced...
They have the right amount of levity, and the right amount of, “Okay, let’s settle down and do something.” They’re just great.

**Program Content: Education.** The participants made several specific comments on the various educational topics presented. Overall, there was the feeling that the content was relevant to the group, even if certain subjects were not necessarily relevant to each class participant. Some participants commented that topics such as airway clearance or travelling with oxygen did not particularly apply to them, but they did see how these topics applied to others. Following are several examples of comments made by the participants on the various educational topics:

**On Pathophysiology of COPD:**
...I’ve always had a bit of curiosity of what makes this hunk of whatever it is, what makes it (the lungs) work...

*I hear the airsacs enlarge and they lose their elasticity...I was very surprised to see where the airsacs were...I didn’t know how it worked. In the class I did. Learned quite a bit, really.*

**On Medication Use:**
...they learn you how to take your medication properly...

**On Energy Conservation:**
*I liked the section on energy conservation. You know, done by the occupational therapist...it was quite specific about conserving energy...*

**On Airway Clearance:**
*The part on airway clearance...was not too helpful for me because I don’t have that problem.*

...Now I do at least once or twice a day, try and cough...I usually get some mucous up when I do that.
The section on nutrition was seen to be of less benefit to several participants, although a few noted that other members of their class appeared to be interested in the presentation. Participants clearly stated that their comments on the nutrition section were their own personal opinion:

_**Nutrition, I mean, we all know what we’re supposed to eat...I think once you’ve reached this age, if you don’t know what you’re supposed to eat and what you’re not supposed to eat, it’s too bad...it’s in the papers, it’s in magazines, it’s on television, nutritionists, and whatnot...**_

_One was the nutrition segment...I can’t think that I learned that much..._

_Diet, which I never did find too interesting. I generally eat what I want, and take a bunch of vitamin pills...I personally was not too interested in dietitians, but that’s not to take anything away from the dietitian._

Overall, the participants found the education sessions to be informative. Participants had purchased the education manual at the beginning of the program and recognized the book as a resource to be accessed when needed after the program.

**Program Content: Exercise.** Each participant was required to exercise and feelings about the exercise sessions were mixed. Many of the participants enjoyed the exercise sessions while others felt the exercise was not particularly necessary or helpful. The overall challenge of the exercise sessions was variable as well. One man with moderate disease did not find the sessions challenging:

_...the exercise program, I think, is fairly useful, but I think you have to be in an advanced stage to be really effective. That was not the effective part for me...those neck exercises,...they’re too basic..._
There were different ideas on the concept of ‘challenging exercise’ however. One participant noted that while the exercises weren’t challenging, she was tired by the end. Another found that although she would only be slightly breathless, she felt she had exercised sufficiently:

... (the exercises) weren’t challenging, but towards the end... I was getting fairly tired...

... mostly I was walking in the hall... it was easy. You know, I just walked at my own pace, and I would be slightly breathless... I’d get a good workout.

It was important for participants to work at their own pace. In addition to the previous quote, a woman with very severe disease commented on how she didn’t feel pressured to compete with anyone else while exercising:

... but then when I found out what kinds of exercise and the fact that you had other people to do them with, and you could do them at your own pace. Now that’s a big thing. You didn’t have to compete with Joe or Janet, you just did your own thing.

Level of disability did appear to have an impact on how participants perceived the exercise. Those participants already active in their day to day lives did tend to find the exercises less challenging than those who were severely disabled by COPD.

**Program Format.** All the participants had many comments on the program format and content. Participants were pleased with the group format, because it allowed them to learn from each other and to understand that there were other people with similar problems as their own. Learning from each other occurred when somebody in the group had an idea or strategy on how to do something easier or better. While the instructors provided basic information, it was often the other members who had experienced problems and came up with creative solutions.
You learn not only from the instructors, but you learn from the other patients.

...the people there will bring out little things that (the staff) didn’t cover...it was what people brought out and how they have solved the problems that apply to all of us...who knows, you may have a hint there that can help somebody else that’s doing it a different way...

Participants appreciated the support and camaraderie of the other members of the group:

...people in the same boat as me didn’t know (about COPD) either, so you didn’t feel like a dummy...

They were all sitting with their puffers in front of them. I felt quite at home there...it was actually very nice for me.

...we were a good bunch...we were probably a little more cheerful than other (groups)...it was good company.

I think this was an exceptional group of people.

Occasionally, participants were frustrated by some class members. The frustration often stemmed from the discussion going off on a tangent, due to a seemingly irrelevant comment made by another participant. One woman said:

One man who took over right from the first day. If I heard ‘his wife was a nurse’ one more time I was going to put my fist down his throat. Who cares?! But other than that, he was very nice. He just sort of dominated.

Participants felt the onus was on the instructor to get the session ‘back on track’ when it digressed. For the most part, the participants felt the program staff was able to do this.

...sometimes when there are time constraints on the speaker, you can’t be that informal. You have to tighten it up and not have so much input from the group...It’s like an oxymoron. You ask for an informal style, but you can’t always adhere to it.
...it's frustrating (when the discussion goes off on a tangent)...but it's hard for the instructors. They tried to answer their questions, but sometimes they would say, "...that will be covered in tomorrow's program" or "If you remember, we covered that last Wednesday."

At Saint Mary's Hospital, each visit to the program consisted of one education session and one exercise session. The class of sixteen was split into two groups of eight. The first group would exercise from 9:30 a.m. to 10:30 a.m., and then assemble for the education session at 10:30 a.m. The second group would arrive at 10:30 a.m. and join in with the first group for the education session, which ran from 10:30 a.m. to 12:00 p.m. The first group would then leave and the second group would then exercise from 12:00 p.m. to 1:00 p.m.

Having two smaller groups exercising instead of one larger group was considered advantageous as there was adequate supervision during the exercise session.

Some of the things I liked about the course was quite a personal approach. You know, the way they divide the class into small groups for the exercises...so there weren't very many people...

However, a few of the participants from the later session felt that their exercise session was often cut short, either because the early exercise session, or the education session, ran overtime. Two women commented:

I have a notion that the 9:30 group got more exercise time in than we did because we usually started about 20 minutes late...we would barely have an hour, not even that, for the exercise time. And the mobility exercises take about 20 minutes...if you're lucky, you're finished in time to do one of the machines or you're walking in the hall.
We were the later class, so our exercise period was always cut short...the other class, I believe, was on the machines and then walking...but I think in our class, you were either walking or on the machines, because the time was too short.

In addition to articulating their impressions of the program, participants were also able to identify what benefits they gained from the program. The next section, ‘Reflecting on Changes’ will describe these benefits in detail.

Reflecting on Changes

The basic objective of respiratory rehabilitation is to provide participants with the knowledge and skills necessary to cope with their disease and to guide them in improving their physical fitness. In doing so, programs hope to effect positive change. However, the provision of these services does not guarantee the change will occur. In this study, the qualitative interview participants were asked to describe the specific changes that occurred for them as a result of the program. Some changes described were relatively basic in that participants learned a particular technique or fact that could be applied to their daily lives. Other changes were more holistic in nature – they encompassed physical, emotional, and psychological domains. When analyzing the data, a process became apparent. This process is illustrated in a concept map (Figure 2.3). The concept map attempts to illustrate the movement from basic change to holistic change. Because the participants had a better grasp of the knowledge, tools and skills needed to make decisions, it gave them greater control over their disease, thereby increasing confidence. The secondary theme, ‘Acquiring Skills and Knowledge’ is considered the most basic of changes. Participants described the specific techniques
Secondary Theme: Acquiring the Skills and Knowledge

* Medication Use
* Energy Conservation and Stress Reduction
  * Breath Control
  * Physical Activity

Secondary Theme: Gaining Control and Feeling More Energetic

* Gaining Control of Breathing
* Gaining Control over Disease
  * Feeling More Energetic

Secondary Theme: Realizing One's Potential

* Feeling Increasing Levels of Confidence
* Feeling Less Socially Isolated
* Changing One's Outlook
* Improving Emotional Well-Being

**Figure 2.3.** Concept Map: Reflecting on Changes
and knowledge they learned. ‘Gaining Control and Feeling More Energetic’, reflects how the acquisition of skills and knowledge gave them greater control over their situation or their reactions. It reflects the skills and knowledge ‘at work’ in the context of the individual, or how the participant used the skill and knowledge to change various aspects of daily life. ‘Realizing One’s Potential’ describes changes that are more abstract in nature. These changes may encompass physical, emotional, spiritual, and psychological aspects of participants’ lives.

Not every level of change was described by every participant. Some participants reflected more on the basic changes and what particular skills and facts they found interesting and helpful. Other participants were vocal about the more abstract changes. They had difficulty identifying exactly what parts of the program helped the most, but they were aware of change that was more abstract or intangible in nature. The following sections will describe each of these secondary themes in greater detail.

**Acquiring Skills and Knowledge.** Although respiratory rehabilitation is often separated into ‘exercise’ and ‘education’, this division can be misleading. A great deal of what a program offers is more than just the delivery of facts and details. Skills and techniques were also taught, and were often reinforced in the exercise sessions. Participants talked about learning about their medications, how to breathe, how to pace themselves and to manage stress, and how to correctly exercise and to walk up stairs.

**Medication Use.** Prior to the program, many participants had not learned proper medication delivery techniques as this is not necessarily part of standard medical
management. The interview participants felt that many of these skills were important to learn.

(We learned) what our medications were, and how you take them. And when you take them. Doctors write you a prescription, and...I was told (before) to put the (inhaler) in my mouth. The puffer right in my mouth...it feels more effective, but it isn't more effective.

(The doctors) kept handing me prescriptions, telling me to use it so many times a day. Not when, if and how.

I learned that Ventolin takes effect in five minutes or so, and the other one, Atrovent, it doesn’t start working for about 15 minutes...(Now I’m) leaving a little more time between taking the puffers...

Energy Conservation and Stress Reduction Techniques. Participants also learned energy conservation and stress reduction techniques. Participants commented that prior to the program, they were less aware of their limitations, and would have low energy. Prior to the program, most participants appeared to have problems with pacing and conserving energy, regardless of their disease severity. They learned about setting priorities and pacing themselves throughout the day. One man with moderate disease commented:

(They taught us about) trying to set your things in orderly fashion, as far as priorities you should have, and so forth. I had my priorities kind of mixed up. I don't think it was too badly mixed up, but I think they’re in much better order now.

A woman with very severe lung disease said:

(They taught us about) how to be prepared for the bad days, and the good days take care of themselves. On bad days you want to have meals on hand that can be thrown in, or be prepared to order in and don’t feel guilty about it...
Breath Control. Learning breath control was identified by all participants as being a key feature of respiratory rehabilitation and led to many of the immediate, positive changes they experienced. Breath control involved slowing down the rate and pattern of breathing in order to reduce airway collapse and alleviate shortness of breath. It is a technique that can be done prior to performing an activity to prevent dypsnea, during the activity, or anytime when an acute attack of dyspnea occurs. The technique of breath control is not intuitive. While some individuals with COPD do it naturally, others need to learn and practice. Two participants found it a difficult habit to acquire but would be reminded to perform breath control when dyspneic and to practice throughout the day:

When I first started out, I'll be huffing and puffing, and then suddenly dawn on me, “Hey, I'm not doing what I should.” And I go back to deep breathing. It's got to become a habit.

I sit there and watch TV or mostly when I'm driving the car I would do this controlled breathing, and when I went for walks, I would do controlled breathing.

Physical Activity. Participants were instructed in the most appropriate types and intensity of exercise for their abilities. This, coupled with breath control, allowed them to learn how to safely exercise. One woman commented on how the program increased the frequency of exercise for her:

I'm doing the exercises five or six times a week...I never believed in exercise (before)...

Acquiring skills and knowledge meant learning about COPD, learning how to use medications, how to pace oneself, how to breathe, and how to exercise. It also
provided the foundation for the next step, and theme, ‘Gaining Control, and Feeling More Energetic’.

**Gaining Control, and Feeling More Energetic.** This secondary theme reflects how acquiring skills and knowledge actually affected the participants. How did using medications correctly, breathing better, pacing oneself, and conserving energy affect the day-to-day lives of these participants? This secondary theme moves away from the descriptions of skills learned to a more contextual understanding of how these skills and techniques affected the participants. Again, not all participants stated the changes they experienced in this context. However, the word ‘control’ came up frequently in all interviews; for example: control breathing, control oneself, or control the situation.

**Gaining Control of Breathing.** Losing one’s breath during activity was a commonly stated problem amongst all participants. For many interview participants, learning how to control one’s breathing using the techniques learned in the program was the highlight of the program.

One man with moderate disease and a woman with very severe disease found that breath control alleviated shortness of breath, and also the associated panic and anxiety:

*The breathing was very much (the key), it saved me from having to rush to emergency last night...knowing how to breathe and how to get myself under control.*

*I brought (my breathing) under control very shortly...just sitting on the side of the bed, and just taking controlled breaths for a period, and just relax...within ten minutes I was okay... (Before) I'd have been gasping and doing silly things...*
Gaining Control Over the Disease. Control also meant feeling in control over one’s disease and its management. One woman with a nursing background used to feel that she should not go to the emergency room even if she had a lung infection, whereas after the program she realized that she needed to begin making the appropriate decisions regarding her health care:

*Now I feel I could...probably manage okay (with a chest infection) and that its okay to go to the hospital, too. Before I went to the class, I thought, I have to stay out of the emergency room no matter what. That’s a disgrace for someone who, with my background, should never find herself in emergency.*

For another woman, control of the disease meant using her medications when she needed to, regardless of who might be watching. Control over her disease meant making the right choices about her treatment, instead of worrying what passers-by might think.

*I am the important one, and if I’m breathless, I need to use this (her puffer) no matter who’s around. Queen of England, or anybody.*

Feeling More Energetic. Being able to control shortness of breath made activity easier. Most participants stated that they had improved fitness levels after the program, evidenced by improved energy levels, increased ability to go up stairs, and increased frequency of exercise during the week:

*My energy level has improved probably ten percent.*

*I got into the exercises and felt one hundred percent better...my energy levels before I started were nonexistent...I would say that they are about three or four times as high as they were...*

*Now it’s a lot easier to go up stairs, and it doesn’t bother me as much, and it’s just quicker...*
Climbing up hills was my big one. I just got quite anxious when I stood at the bottom of a lot of stairs, or a hill, and I would look up at it and I would think, “I don’t know how I’m gonna do this”...(Now I can)...

Other people in the room kept saying, “You know, I feel quite a bit better since I started coming here” and I got to thinking, “Yah, I do too.” I could walk up the hill to my car quite a bit better...when I came home, I heard that other people would just lie down all afternoon, but I didn’t do that...oftentimes I went somewhere else.

For many of these participants, gaining control over their breathing, feeling more in control of their disease management, and feeling more energetic were incredible changes. They began to see themselves in a new light; they realized that they were capable of greater physical activity than they previously thought, and they felt more in control over COPD, instead of feeling like COPD was controlling them. These changes were important ones for the participants, and they led to more powerful ones. The final section discusses how feeling more in control and more energetic allowed a few of the participants to realize other goals in terms of increasing confidence levels, reducing social isolation, and improving emotional and physical overall well-being.

Realizing One’s Potential. By the time many of these participants had come to respiratory rehabilitation, they had been living with COPD for several years. Some had experienced the disabling symptoms long before they received their diagnosis. Consequently, how they viewed their future was significantly impacted by this diagnosis. Most of the participants commented on how the program overall had changed their lives, their outlook, and their beliefs in their own potential. Participants
also commented on how their confidence in themselves and their improved physical status allowed them to increase their social activities. Realizing one’s potential is the most abstract of the themes presented. It describes changes which are not easily linked to a specific intervention, but instead are testimonial to the overall effectiveness of the program.

**Feeling Increased Levels of Confidence.** Several participants commented on how the control over their breathing and the increased energy levels allowed them to feel confident again.

*I felt like I had control over my everyday actions. I felt quite confident, I could go anywhere, more or less, do things that I had to do.*

*I know how to control the situations I have...I feel now confident if I have a shortness of breath, I can control it to the point where I don’t have to go (to emergency).*

**Feeling Less Socially Isolated.** Feeling more confident and more energetic allowed a few of the participants to begin increasing their activities outside of the house. For the two women with very severe COPD, this represented a major change in their lifestyle. They had been practically housebound prior to the program, but they began to feel more confident and began going out of the house:

*My calendar is absolutely full. (Before), I could be in for two to three weeks. Now I’m out three or four times a week... (It’s a) huge, huge change...*

*...I got to the point where before I took this course I didn’t want to go out at all. Because everybody was looking at me, because I would get myself into these situations... (Now, my social life) is greatly improved... If people say, “Come down to the green and watch this game,” I’ll go, you know. Previously, oh no, I couldn’t go there.*
Changing One’s Outlook. Several participants noted that they viewed themselves and their bodies differently after the program. They felt proud of their accomplishments, and felt the program offered motivation and incentive to keep trying.

I’ve gotten over the feelings that things have to be done once you don’t do them yourself. But the fact I could do them myself made a tremendous difference.

My body feels better, ... and when I get up to go, I feel a little bit lighter. You know, my body feels lighter...

I was surprised to find out, no matter how bad you are, and I mean I am in fairly bad shape, you can still improve a bit.

What I really needed was the whole picture. And the motivation it gave me... I got the motivation, that’s a big thing, and nobody can give it to me...

I really had to push myself because I hadn’t been doing anything for awhile... (my husband) was spoiling me rotten and killing me...

The last two participants quoted realized that the motivation and determination had to come from within themselves.

Improving Emotional Well-Being. Perhaps the most striking of all changes were the changes to the emotional health of two participants. These two women with very severe disease realized an improvement in their psychological well-being as a result of the program. They attributed their emotional decline to the symptoms of COPD, such as dyspnea and fatigue. When they were able to actively alleviate some of these symptoms, their emotional health improved as well, and was noticed by those close to them:
I didn’t get excited about anything. I didn’t think I was depressed. But I didn’t feel great pleasure about anything, or great remorse about anything. I just went from day to day...I’d been in the program...about three or four weeks, and we were sitting watching television...and it was particularly funny. And it just tickled my funny bone and I started to laugh. And I couldn’t stop laughing. And all of the sudden I looked at my husband and he wasn’t looking at the television. And I said, “What’s the matter?” and he said, “You know this is the first time in about three years I’ve seen you laugh?” Now, it’s not depression that kept me from laughing, it was fear of losing my breath...(Now) it’s wonderful! It’s just marvelous. To hear a joke and laugh at it...after years I have been able to laugh again. And enjoy.

I could see I was getting worse, and I didn’t know how to stop it...So I thought to myself, “Oh, I’m going down the hill pretty fast. I’m on a slippery slope here.” But the course has given me hope, and not only hope, but how to achieve it, you know...now I feel stronger...and even people on the phone say, “My goodness, you sound so strong”...mentally I’m strong, a lot stronger.

In summary, three main themes were obtained from the data: How Participants Came to Respiratory Rehabilitation, their Impressions of the Program, and the Reflections on the Changes they experienced. Several secondary themes were also identified. Overall, the participants felt the program was beneficial in improving their ability to handle their shortness of breath, improve their fitness and energy levels, and increase the feelings of confidence. These themes and secondary themes are summarized in Table 2.14.

**DISCUSSION**

The results of this study show an improvement in QOL in individuals with COPD after a five-week respiratory rehabilitation program. Specifically, this study
found improvement in the CRQ’s Physical Function component and Emotional Function component, and in the SF-36’s Physical Summary component. The Mental Health Summary component of the SF-36 did not show improvement in emotional or mental health aspects of QOL in this sample. The group had stability in airflow limitation as shown by no change in FEV₁. These results support the hypothesis for this study, with the exception of the lack of change in the Mental Health Summary for the SF-36.

The inclusion of the qualitative data broadened the scope of QOL assessment, and not only identified the presence of change, but also identified the manner in which respiratory rehabilitation affected QOL changes in some individuals. The changes detected by three of the four quantitative components were enhanced and complemented by the statements given by the qualitative interview participants. These individuals were able to identify what they liked about respiratory rehabilitation and how the respiratory rehabilitation program changed aspects of their physical, emotional, and social health.

Quantitative Data

Baseline Measurements

The baseline measurements of age, gender and disease severity of this sample were similar to other studies assessing respiratory rehabilitation. The mean age of this sample tended to be slightly older but with similar severity of lung disease. The baseline scores for the CRQ and the SF-36 were also similar to those measured in individuals with COPD in previous studies although the scores for the SF-36
tended to be higher (indicating a greater QOL) in this study than the norms published for COPD in the U.S. population. However, the characteristics of the U.S. COPD population were not provided, so comparison between this study and the U.S. study was limited.

*Physical Function Score Changes*

The significant improvement noted in QOL as measured by the Physical categories of the CRQ was consistent with the changes reported in previous studies of respiratory rehabilitation using the CRQ. Wijkstra et al demonstrated a significant 22% increase in Physical Function in the CRQ after a 12-week home-based rehabilitation program. Goldstein et al reported an increase of 30% in the CRQ's physical domains after a 4 to 6 week inpatient program. Of note, both of these studies also reported improvements of a similar magnitude as this study. In two separate studies, Guyatt et al also showed results that were consistent with those from this study. Finally, a meta-analysis of respiratory rehabilitation reported a similar trend in improved Physical Function of the CRQ. Comparisons of the SF-36 between this study and others are not possible, due to lack of COPD clinical trials in respiratory rehabilitation utilizing the SF-36.

The ability of the questionnaires to detect change in physical activity corresponds with the findings from previous studies that assessed exercise tolerance after rehabilitation. Numerous studies have shown improvement in six-minute walk distance, work tolerance, maximum oxygen consumption, blood lactate levels, and workload after a trial of respiratory rehabilitation. The respiratory
rehabilitation programs in this study provided at least one hour of exercise three times per week for 5 weeks. It is expected that this amount of exercise training would result in improvements in exercise tolerance\(^{42}\) which could then be detected by the physical categories of the questionnaires, as the questionnaires have items which measure the ability to perform activities or the dyspnea and fatigue associated with certain activities.

Although the CRQ did show a highly significant change in physical function after rehabilitation, this questionnaire does not address the ability of an individual to perform specific activities routinely performed in daily life, such as walking, climbing stairs, dressing, or bending. This may be a limitation of the questionnaire. The dyspnea domain in the CRQ does measure the amount of dyspnea experienced while doing physical activities, but it does not clarify an individual’s ability to perform physical activity. Consequently, those individuals who have severe physical limitations would not have their limitations addressed by the questionnaire. For example, there were several subjects in this study who had limited their activities to the point where they rarely left their chair. As they did not perform physical tasks, they did not experience a great deal of dyspnea. They rarely exerted themselves. Therefore, their Physical Function score on the CRQ was not particularly low. However, had there been questions on their ability to perform common physical activities such as walking, dressing, bathing, or bending, they might have scored much lower. In addition, improvements in their overall ability to perform these activities could then be measured after rehabilitation. Improvements in these features due to improved fitness levels after respiratory rehabilitation would not be measured by the CRQ and could be considered a threat to content validity in this questionnaire.
Although the SF-36 did detect an improvement in physical function, the magnitude of change was less than that detected by the CRQ. Although the SF-36 has many items that measure the ability to perform basic activities, it also has several questions that ask the individual’s ability to perform strenuous activities, such as running, walking up several flights of stairs, or walking more than a kilometre. Participants may not have an improvement in physical function to the degree they can now run or walk long distances. For some people, being able to walk in their home with ease would be a great improvement. In addition, the Bodily Pain domain would not be expected to change, as COPD is not associated with pain symptoms. These items which do not change after rehabilitation may reduce the sensitivity of the questionnaire to detect change in the other, more relevant items. This may explain the difference in the magnitude of change in Physical Function between the generic and the disease-specific questionnaire.

Emotional Function and Mental Health Score Changes

In addition to the improvements in Physical Function, the CRQ also recorded changes in Emotional Function. This finding is also consistent with those from previous studies.\textsuperscript{2,8,18,32} A meta-analysis evaluating respiratory rehabilitation outcomes pooled the results from five studies using the CRQ and found the effect size for both domains of the CRQ’s Emotional Function component exceeded that required for a minimal clinically significant difference.\textsuperscript{35} The ability of the CRQ to detect changes in emotional function may be due in part to the items represented. The CRQ has several items that assess feelings of confidence, control, happiness, and depression. Changes in
these items are possible after respiratory rehabilitation, and were confirmed by several of the interview participants. Improvements in exercise capacity has also been shown to have a positive effect on depression.43-45

In this study, the Mental Health Summary of the SF-36 did not show a significant difference after rehabilitation. This finding is interesting, considering the significant change seen in the Emotional Function component of the CRQ. Our results illustrated the lack of responsiveness of a generic questionnaire versus a disease-specific questionnaire. When the questions that make up this component in both questionnaires were compared, one key difference arose. The CRQ asked the individual to measure fear, panic, and anxiety when short of breath, as well as the individual’s sense of control and confidence over COPD. Improvements in an individual’s ability to control their feelings of panic or dyspnea could translate to a higher score in this component. The respiratory rehabilitation program did teach subjects various skills to reduce dyspnea and panic, as well as techniques designed to reduce stress. As the SF-36 had no questions that related to dyspnea, panic, or gaining control, it was likely the questionnaire could not detect these changes. This may account for the relative lack of responsiveness of the Mental Health Summary component of the SF-36.

Emotional improvements after rehabilitation may depend in part on the instrument. One study46 that looked specifically at psychosocial attributes such as depression and anxiety using the State Trait Anxiety Inventory and the Zung Self-Rating Depression Scale found equal changes in psychosocial status in both the control and the rehabilitation group. However, this study had the ‘control’ group do no
exercise for the first fourteen weeks then cross over to the rehabilitation group; whereas the rehabilitation group exercised for the full 28 weeks. Fourteen weeks of exercise in the ‘control’ group may have caused the improvement; therefore the findings of this study may be inconclusive. Ries et al\textsuperscript{1} found improvements in self-efficacy after rehabilitation, but no change in the score of the Quality of Well-Being Scale or the CES-D Depression scale. Conversely, Dekjuijzen et al\textsuperscript{47} found significant reductions in depression and anxiety after rehabilitation using the Hospital Symptom Checklist, but no changes in social inadequacy or self-esteem using the Dutch Personality Inventory. Other studies have shown significant reductions in distress, depression, or anxiety.\textsuperscript{32,48} The psychological components of QOL instruments and the various psychological questionnaires may show different findings due to the large variety in psychosocial attributes that can be measured, and how those attributes are defined.

\textit{Trends of Change Between Physical Function and Emotional Function/Mental Health}

The Physical Function components from both questionnaires showed the largest magnitude of change compared to the Emotional and Mental Health components. This is an interesting finding, considering that the interview participants commented on both physical and emotional changes. Although the prevalence of depression in COPD has been documented (see Chapter One), it would appear that for our group of study participants either greater changes were reported in physical ability, or the questionnaires’ evaluation of emotional health was less sensitive to change than those of physical health.
The relative impact of rehabilitation on emotional versus physical function must also be considered. In COPD, physical aspects of QOL may tend to be lower compared to the normal age-matched population, whereas emotional function may be similar to normal reference values. This hypothesis is corroborated when assessing the normal SF-36 scores for the age-matched U.S. population. The U.S. population score for the Mental Health Summary scale for those 65-74 years old is 52.68, and for those 75 and over, the score is 50.44. Yet 69% of the sample from this study had a score greater than or equal to 50, which indicates a Mental Health Summary near the U.S. norm. Therefore, it is conceivable that there would be smaller improvements to emotional health after respiratory rehabilitation in those who show baseline values similar to normal reference levels. Further studies may reveal how the emotional aspects of QOL in COPD are affected after rehabilitation, whether or not QOL questionnaires assess the most relevant aspects of emotional health in COPD, and whether direct comparisons of physical and emotional function are possible.

**Test-Retest Reliability**

The test-retest reliability of the CRQ, the SF-36, and the SIP were also studied. Even with a small sample size (n=10), all three questionnaires showed high reliability coefficients. These numbers are higher than other studies examining the test-retest reliability.\(^{34,49,50}\) One reason for this may be extra care in this study to exclude anyone with unstable lung disease, chronic asthma, or other unstable or severe comorbidities. Excluding these subjects may allow for more stability of test scores due to stability in QOL.
Interview Data

The qualitative data yielded information on how a subsample of seven subjects accessed the rehabilitation program, the impressions they held of the program, and the changes they noticed as a result of the program. For many of these seven individuals, accessing the program involved accepting the referral made by the doctor. There were a range of different expectations held by the subjects prior to beginning the program; however, those with few expectations of the program did notice similar benefits as those who had specific goals. Low levels of motivation prior to entering a program may not be a predictor of poor outcome.

Respiratory Rehabilitation as a Form of Adult Education

Once in the program, subjects were exposed to various educational and exercise modalities. Although opinions were mixed about the relative benefits of the various educational topics, there was consistent agreement among the seven subjects on the overall high quality of the program. The numerous positive compliments on the program format and staff indicate a firm commitment on the part of the program organizers to provide a quality program which conform to the tenets of adult education. Malcolm Knowles, considered by many to be the leader of adult education, provided several assumptions about adult education, or ‘andragogy’, that included understanding the adult learner, appreciating the role of the learner’s experience, being aware of the readiness of the learner to learn, and understanding how adults apply their learning. The respiratory rehabilitation program in this study met many of these assumptions for adult learning. They provided an adult learning environment, utilized the shared
experiences of the group, and introduced skills and knowledge which were immediately applicable to the participants' lives.

*Respiratory Rehabilitation and Its Influence on Quality of Life*

The seven qualitative interview participants described several aspects of their lives that changed after the rehabilitation program. These changes were described in the results section using a concept map to illustrate the move from changes that appeared concrete and tangible to those that were more abstract in nature. How do these changes in turn lead to an overall improved QOL? The concept map introduced in the results section with an additional hypothesized link to QOL will describe this process (Figure 2.4).

Participants described the acquisition of particular skills and knowledge, such as learning breath control, learning how to exercise, and learning how to use their medications. However, the mere acquisition of knowledge and skills does not necessarily have a positive effect on QOL. Health education researchers have confirmed that the most effective health education programs work toward changing attitudes and behavior, in addition to increasing knowledge and awareness. Steckler et al. described the relationship between intervention and changes in health status (Figure 2.5). They state that, “health education intervention strategies can affect intermediate outcomes (e.g. changes in knowledge, attitudes, or behavior) which in turn may affect identifiable and measurable changes in health status.” Using this model, they then list the factors which facilitate successful (i.e. improving health status)
Secondary Theme: Acquiring the Skills and Knowledge
* Medication Use
* Energy Conservation and Stress Reduction
  * Breath Control
  * Physical Activity

Secondary Theme: Gaining Control and Feeling More Energetic
* Gaining Control of Breathing
* Gaining Control over Disease
  * Feeling More Energetic

Secondary Theme: Realizing One’s Potential
* Feeling Increasing Levels of Confidence
  * Feeling Less Socially Isolated
  * Changing One’s Outlook
  * Improving Emotional Well-Being

Improved Quality of Life

Figure 2.4 Concept Map: Reflecting on Changes -- Modified
Figure 2.5  Adapted from Steckler et al's Figure: Relationship between intervention and changes in health status.
intervention level strategies. One necessary element is that the intervention strategy must encompass a range of educational and behavioral strategies, including goal setting, coping thoughts, self-control strategies, and guided practice of desired behaviors.

The respiratory rehabilitation program in our study utilized many of these strategies. It provided basic education as well as aided the participants in defining their individual goals for improvement. It also reinforced various coping strategies, such as energy conservation, and self-control strategies, such as breath control, by teaching and then practicing them throughout the program. The secondary theme ‘Gaining Control and Feeling More Energetic’ can be thought of as the changes noticed by the participants as a result of learning and utilizing the various behavioral strategies designed to improve the ability to cope with COPD.

**Coping with COPD.** The concept of coping with chronic illnesses such as COPD has been well-documented in the literature. Coping is defined as ‘efforts to master stressors when a routine or automatic response is not readily available.’\(^{53}\) Cohen and Lazarus\(^{54}\) have defined five main coping modes. The first, ‘information seeking’ describe how individuals with chronic illness seek only the necessary information for the given moment. The second, ‘direct action’ states that people with chronic illness take action aimed either at the self or the environment in order to alter stressful situations. The third mode, ‘inhibition of action’ states that often effective coping requires the individual to avoid certain actions which could cause harm. The fourth mode, ‘the intrapsychic process’ is simply what the individual is saying to himself about the chronic illness. This can include rationalization, denial, as well as
relaxation techniques and mentally re-appraising situations. The final mode, 'turning to others' involves the access of long-term support when coping with chronic illness.

In our study, respiratory rehabilitation provided or encouraged all five modes of coping. It attempted to individualize the program for each participant while it recognized that there are many similarities of problems within COPD. It also provided a mode of direct action, by teaching and reinforcing the actual physical techniques required to enhance coping, such as breath control, medication use, and physical exercise. It also instructed the participants in how to avoid or inhibit certain actions, by teaching stress reduction and energy conservation techniques. Although psychological counseling was not a part of the programs in this study, the respiratory rehabilitation programs did attempt to focus on adaptive mental processes, including motivation strategies, and discussions on self-esteem and acceptance. In addition, the participants commented on how they felt better about themselves after rehabilitation, which indicates a change toward more adaptive, rather than maladaptive, strategies. Finally, the respiratory rehabilitation programs provided an avenue for social support. The qualitative interview participants commented on how much they appreciated the support from both the program staff and the other participants.

Other researchers have commented on the necessity of appropriate coping strategies for individuals with COPD. Janelli et al\textsuperscript{55} found that the five most common coping strategies for individuals with COPD (measured with the Jalowiec Coping Scale) were: thinking about different ways to handle the situation; worrying; blaming others for the problem; letting someone else solve the problem; and taking drugs. With the exception of the first one, these strategies tend to be somewhat passive in nature.
They imply the individuals felt a lack of control over the disease. Participants from this study stated similar strategies. They also commented on how they had reduced activity, experienced more anxiety, and felt guilty and embarrassed about their disease. The participants replaced many of these maladaptive strategies with ones which enhanced their ability to cope. This in turn led to an increased sense of control over their disease, which in turn enhanced their confidence, improved their social role, and improved their emotional well-being.

**Control in COPD.** Control in chronic illness has been discussed in the literature, both in COPD and in general. Folden reported that after desiring improved functional ability and decreased respiratory symptoms, individuals with COPD were most likely to report a desire for increased control over COPD. In our study, control was a predominant theme. The word came up in many of the interviews: control over breathing, control over the situation, control over COPD. Control as an outcome is also apparent in the CRQ, which asks several questions about the individual's sense of control. Because COPD is associated with dyspnea, and dyspnea is often linked with anxiety and panic (see Chapter One), control over breathing may lead to a sense of control over the disease.

By feeling in control of the disease and the additional benefit of improved physical fitness after rehabilitation, many of the interview participants commented on an improvement in social activity.

**Social Isolation and COPD.** Social isolation in COPD has been reported and has been postulated to be a result of physical disability and negative self-perception. The qualitative interview participants corroborated this hypothesis when


they discussed how their increased energy, ability to deal with shortness of breath, and diminished embarrassment about their disease resulted in their increased activity outside the home.

**Emotional Expression and COPD.** Individuals with severe COPD have been described as being in an "emotional straitjacket". Dudley et al. reported that patients with severe COPD had difficulty expressing anger, depression, or happiness because these emotions could lead to distressing symptoms, specifically dyspnea and anxiety. In this study, one woman with very severe COPD commented on this phenomenon. She acknowledged that for several years, the fear of losing her breath had prevented her from laughing. She could attribute her improved emotional well-being to first learning how to control her breathing, and then feeling confident that she could control her breathing when she needed to.

**Quality of Life.** The previous sections described how the intervention strategies of respiratory rehabilitation produced the intermediate outcomes of improved coping strategies, increased confidence and control, improved physical ability and energy levels, decreased social isolation, and improved emotional well-being. In Figure 2.5, health status is ultimately improved via the attainment of the intermediate outcomes. Fundamentally, the question arises: does respiratory rehabilitation improve QOL? No qualitative interview participant specifically stated that his or her 'quality of life' was improved. However, if we acknowledge that QOL encompasses such attributes as sense of well-being, emotional functioning, social role functioning, activities of daily living and recreation, as well as coping style and self-image, we can see how many of the changes identified by the interview participants indeed could be
considered changes in attributes of life quality. The changes in life quality appeared to be due to the changes described by the second theme, Gaining Control and Increasing Energy Levels, as well as changes described in the third theme, Realizing One’s Potential (Figure 2.4).

The qualitative interview participants were able to identify several areas of change that correspond to QOL attributes. The questionnaire data also identified improvements in QOL. The integration of this data allows for a comprehensive understanding of how QOL is affected after respiratory rehabilitation, and demonstrates the usefulness of mixed-methods research in rehabilitation evaluation.

Integration of Questionnaire Data and Interview Data

In this study, the combination of both quantitative and qualitative data collection methods allowed for a more comprehensive assessment of QOL than could be achieved by the quantitative method alone. The quantitative data provided a wealth of information on the magnitude of QOL change in a group of individuals with COPD. It also characterized that change by measuring physical health perceptions as well as emotional health perceptions. The quantitative analysis also ensured the validity of the data, with large significant changes recorded during the Rehabilitation Phase that were not evident during the Control Phase. It also provided further assurance of the usefulness of the CRQ in measuring QOL in this population.

The qualitative data provided invaluable descriptions of the experiences of a subsample of individuals. Without the qualitative data, there would be little understanding of the mechanisms behind the QOL changes in these individuals. The
qualitative data provided rich descriptions on the process of change. A pathway was postulated that described how acquiring the knowledge and skills led to a greater sense of control over breathing and the disease, which in turn led to increased confidence levels, physical abilities and emotional well-being. In addition, the qualitative data provided information on what expectations and attitudes the seven participants held prior to rehabilitation, as well as their opinions and comments about the program content, format, and staff. Thus, the interviews provided a greater variety of information on the program than that provided by the questionnaires. These additional findings provide helpful information to those interested in the evaluation of respiratory rehabilitation from a quality improvement perspective.

There was very little contradiction between the quantitative findings and the qualitative findings. The questionnaires measured a significant improvement in physical function, a finding that was voiced by the seven interview participants. They commented on improved energy levels, increased ability to perform specific activities, and reduced shortness of breath when doing those activities. The changes in the CRQ Emotional Function component were also similar to those statements made by the seven interview participants, who spoke of increased control and confidence and improved emotional health. As the difference in the CRQ scores exceeded that of the minimal clinically significant difference, the magnitude of change also appeared to correspond with the comments of the interview participants. Lack of change measured by the Mental Health Summary of the SF-36 may be due in part to the lack of questions regarding confidence and control, an important aspect of change reported by the interview participants.
It can also be useful to assess how the individuals who participated in the interviews scored on their questionnaires. Tables 2.11 and 2.12 show the individual scores for all the study participants. The interview participants are shown in italicized print. Participants 1,5,16, 17, 25,33, and 42 were interviewed. Participant 1 showed very little change in either questionnaire. In the interview, she found it difficult to identify specific changes, but had made positive general comments about the program. Participant 16 had little physical change in the CRQ and the SF-36. He confirmed this finding during the interview when he stated the physical training was not challenging for him. Participant 42 had very severe COPD, and had large changes in her CRQ physical and emotional scores, although not on her SF-36 scores. She spoke of the greatest changes in terms of physical ability and emotional status. The other participants had a variety of change or no change in the four separate categories. Comparing the individual scores in this way can provide a greater awareness of the data, but as the interview participants were not selected based on their scores, it is difficult to make any firm conclusions regarding individual scores and individual interviews.

Additional Findings

Although the purpose of this study was to assess the changes in QOL after respiratory rehabilitation, information on other related topics was obtained. The seven qualitative interview participants talked about various aspects of their medical care, including how they were referred to the program and what expectations they had prior to starting rehabilitation. The seven interview participants repeatedly commented on
how understanding what COPD was and how to use their medications was important, and contributed to their sense of control over the disease. The relative lack of knowledge of COPD and medications in this group was a startling finding. However, this problem has been reported before. Koning et al\textsuperscript{65} noted that more than 50\% of subjects wanted more information about respiratory illness, and 48\% wanted more information about the results of diagnostic tests. In particular, they wanted to be better informed about their own illness and prognosis and about their prescribed medications. Several of the seven interview participants in this study commented that they were handed a prescription for inhalers with no instruction on how to use them. Inhaler medications are somewhat unique in that they often require a certain amount of judgment on the part of the individual with regards to when to take them, as well as considerable dexterity and coordination in order to administer them correctly. Learning how to properly use an inhaler, understanding how each medication worked and understanding how to obtain the greatest benefit from the medications contributed to the sense of control over the disease. Proper use of medications may aid in controlling breathlessness and improving physical function.

Limitations of the Study

There were some limitations to this study. The lack of a random sample does reduce the generalizability of the results. Participants in this study would not necessarily be representative of COPD at large, because they have shown a level of motivation and interest in respiratory rehabilitation which does not occur in all people with COPD. However, respiratory rehabilitation is not a passive process, and success
of the program rests in part on the ability of the individual to incorporate the skills and knowledge in his or her daily life. It is unrealistic to expect the same improvements in a randomized sample of subjects with COPD if a percentage of the sample is not motivated to participate.

This study does not show the lasting impact of respiratory rehabilitation, as the final testing session occurred at the end of the program. Repeating the testing at six months to a year would show if these changes in QOL were maintained after the program end.

There were no objective tests to corroborate the physical scores of the questionnaires. However, other studies of respiratory rehabilitation have shown changes in exercise tolerance, and the purpose of this study was to specifically assess QOL changes as perceived by the individual. As several interview participants commented on how the rehabilitation improved their ability to perform specific activities, including instruments designed to measure functional ability, such as ADL measurements might have provided further information on how respiratory rehabilitation impacts QOL.

Both the Hawthorne effect (whereby a study participant alters behavior because of the circumstance of being studied) and the problem of participants telling the researcher what they think she wants to hear are threats to the validity of the results of this study. Without objective measures, it is difficult to determine the magnitude of both validity threats. However, objective measures of QOL are contradictory to the basic definition of QOL, in that it should be as perceived by the individual. Nevertheless, the researcher attempted to minimize the effects by dissociating herself
from the program as much as possible, and asking specific questions about the strengths and weaknesses of the program.

The small numbers of individuals who participated in the qualitative interviews is another limitation of this study. It is difficult to know if the opinions and experiences of the seven individuals would be shared by the overall study sample of twenty-nine people. Increasing the number of qualitative interviews would enhance the rigour of the qualitative methodology of this study.

One other limitation of this study is the lack of application of these findings to members of various ethnic groups and backgrounds. As all the participants in this study were white, it is unclear whether these changes and comments would have been the same had the sample consisted of individuals from other ethnic or cultural backgrounds. Further research focussing on the changes in QOL after rehabilitation in individuals with COPD from other ethnic groups would aid in ensuring that respiratory rehabilitation provides culturally sensitive information while still respecting the unique needs of the individual.

Implications of this Study

There are several important implications to the findings of this study.

1. The relative responsiveness of the two questionnaires in assessing QOL has been determined. The CRQ does appear to be a more responsive QOL instrument in this population. The SF-36's lack of responsiveness in assessing emotional health limits its usefulness in both the clinical and research setting, as emotional or psychosocial health is an important aspect of COPD.
2. Understanding the manner in which QOL is impacted by respiratory rehabilitation is extremely important to those working in the area and those involved with the design and evaluation of the program. Subjects were able to identify which aspects of the program were the most beneficial – these areas should be assessed in all programs to ensure they are meeting the participants needs. Clinical competency is also an important dimension in respiratory rehabilitation and should be reviewed periodically.

3. The combination of methods in this study yielded results that could not have been deduced by either method alone. The quantitative results yielded trends that could be applied to respiratory rehabilitation participants in general, whereas the qualitative data expanded the analysis of QOL by providing contextual information on the process of QOL change in the smaller group of seven individuals. In this study, the combination of methods improves the validity of the study and provided a comprehensive assessment of QOL change after respiratory rehabilitation in individuals with COPD.

Concluding Remarks

The impact of COPD on QOL is variable, but as the disease progresses, QOL suffers. The findings from this study have provided a greater understanding of how QOL is impaired in COPD and how respiratory rehabilitation works to reverse this problem.
Understanding QOL after Respiratory Rehabilitation

Although QOL questionnaires have been previously used in respiratory rehabilitation evaluation, there has been little analysis on how changes in QOL occurred. Researchers have called for further studies which would assess the separate components of respiratory rehabilitation in order to determine their relative contribution to the overall benefits; however, this approach may be limited. The individual components may be interactive in nature and their benefits may not be shown if studied in isolation.

The use of mixed-methods research in this study may have, in part, addressed this issue. While quantitative results reported overall effects, the qualitative results outlined the relative benefits of the specific components as experienced by a smaller group of individuals and were used to postulate a pathway of improvement in QOL, which may represent an improved understanding of the process of QOL change after respiratory rehabilitation.

Putting Quantitative Results into Context

One benefit of qualitative research in this study is that it placed the benefits of QOL, as measured by the three categories of the two questionnaires, into context. It can be difficult to translate the mean changes of a group into an accurate understanding of QOL in an individual. The qualitative data provided that understanding by describing the myriad of ways QOL is impacted after rehabilitation.
Mixed Methods in Program Evaluation

While mixed methods have been utilized in other evaluations of programs, its use in respiratory rehabilitation has been minimal. The findings from this study illustrate merely one way an outcome of interest could be measured. Other subjective phenomenon could also be effectively assessed. For example, the experience of depression in COPD appears to be widespread. Determining if and how respiratory rehabilitation impacts depression could be accomplished using mixed methods. Research on anxiety, social isolation, and stress in COPD after respiratory rehabilitation are also amenable to mixed methods studies.

Refinement of Questionnaires

The qualitative data in this study provided some valuable feedback on the usefulness of the two QOL questionnaires in respiratory rehabilitation. This feedback could result in the further refinement of the questionnaires. The lack of questions on physical ability in the CRQ meant that improvements in this area would not be detected. Perhaps further refinement of the questionnaires could improve their sensitivity. Several of the themes identified in this study were similar to the domains measured in the CRQ, which reinforced the content validity of the questionnaire. Questionnaire refinement in the form of physical ability questions for the CRQ or a COPD supplement for the SF-36 are also possible considerations.
Improving Respiratory Rehabilitation

Improving the quality of respiratory rehabilitation is important to researchers, clinicians, and program staff. It can be difficult to determine what areas of a program are beneficial and what areas may need strengthening. The results from this study begin to identify what program participants find beneficial. Staff from rehabilitation programs could then assess their own programs to determine the relative strengths and weaknesses of the various components. For example, the lack of challenge noted by some participants during the exercise sessions is an important finding. All respiratory rehabilitation programs should assess their exercise component to determine if each participant is sufficiently physically challenged, with an appropriate exercise prescription and clear goals for improvement.

Future Considerations for Research

This study has provided information that would benefit from further exploration. In addition to the refinement and subsequent further testing for the questionnaires, as measured above, there are several other research questions which could be addressed. Further studies on the concept map of QOL changes in respiratory rehabilitation are required. Is gaining control the key link to improved QOL, or are there other processes at work? Is this pathway consistent, or are there parallel pathways that can also lead to improved QOL? Does this path occur in all individuals, or are there intervening variables, such as disease severity? Do men and women experience respiratory rehabilitation differently, and if so, does the program adapt to their different needs? Do different ethnic and cultural backgrounds have different needs, and are
programs flexible to adjust to these needs? How does gaining control over the disease impact the prognosis of the disease? Do changes occur in the frequency and manner of health care utilization? And finally, are these changes in QOL unique to COPD? Would individuals with other chronic lung diseases experience improvement in QOL in similar ways?

SUMMARY AND CONCLUSION

This study has shown that respiratory rehabilitation improves QOL in individuals with COPD. Respiratory rehabilitation is able to improve QOL by delivering exercise training, education, support, motivation, and coping strategy techniques to a group of motivated individuals with COPD. In addition, the success of the program is enhanced by the excellence of the program staff in delivering the program content. These findings are confirmed in this study using the results from two types of quantitative QOL instruments, a disease-specific questionnaire and a generic questionnaire, and from the qualitative data obtained from the interview participants.

This study provides a foundation for further identification of the processes of QOL improvement after respiratory rehabilitation in individuals with COPD and provides direction for research addressing the impact of disease, age, gender and severity on QOL after rehabilitation. By expanding the assessment of QOL to include methods from both quantitative and qualitative paradigms, researchers and clinicians alike can begin to unravel the processes behind the benefits achieved after respiratory rehabilitation.
REFERENCES


12. McHorney CA, Ware JE, Raczek AE. The MOS 36-item Short Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care 1993; 31:247-263.


33. Couser JI, Martinez FJ, Celli BR. Pulmonary rehabilitation that includes arm exercise reduces metabolic and ventilatory requirements for simple arm elevation. Chest 1993; 103:37-41.


Sickness
Impact
Profile

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MARILYN BERGNER
Once you have started the questionnaire, it is very important that you complete it within one day (24 hours).

If you find it hard to keep your mind on the statements, take a short break and then continue. When you have read all of the statements on a page, put a check in the BOX in the lower right-hand corner. If you have any questions, please refer back to these instructions.

Please do not discuss the statements with anyone, including family members, while doing the questionnaire.

Now turn to the questionnaire booklet and read the statements. Remember we are interested in the recent or longstanding changes in your activities that are related to your health.
Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. I spend much of the day lying down in order to rest</td>
<td>(070-083)</td>
</tr>
<tr>
<td>2. I sit during much of the day</td>
<td>(062-049)</td>
</tr>
<tr>
<td>3. I am sleeping or dozing most of the time - day and night</td>
<td>(063-104)</td>
</tr>
<tr>
<td>4. I lie down more often during the day in order to rest</td>
<td>(066-058)</td>
</tr>
<tr>
<td>5. I sit around half-asleep</td>
<td>(065-084)</td>
</tr>
<tr>
<td>6. I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently</td>
<td>(069-061)</td>
</tr>
<tr>
<td>7. I sleep or nap more during the day</td>
<td>(071-060)</td>
</tr>
</tbody>
</table>

Check here when you have read all statements on this page □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I say how bad or useless I am, for example, that I am a burden on others
   
2. I laugh or cry suddenly
   
3. I often moan and groan in pain or discomfort
   
4. I have attempted suicide
   
5. I act nervous or restless
   
6. I keep rubbing or holding areas of my body that hurt or are uncomfortable
   
7. I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen
   
8. I talk about the future in a hopeless way
   
9. I get sudden frights

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I make difficult moves with help, for example, getting into or out of cars, bathtubs (168-064)
2. I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid (170-121)
3. I stand only for short periods of time (155-072)
4. I do not maintain balance (146-098)
5. I move my hands or fingers with some limitation or difficulty (152-064)
6. I stand up only with someone’s help (165-100)
7. I kneel, stoop, or bend down only by holding on to something (171-064)
8. I am in a restricted position all the time (156-125)
9. I am very clumsy in body movements (148-058)
10. I get in and out of bed or chairs by grasping something for support or using a cane or walker (169-082)
11. I stay lying down most of the time (162-113)
12. I change position frequently (147-030)
13. I hold on to something to move myself around in bed (143-086)
14. I do not bathe myself completely, for example, require assistance with bathing (310-089)
15. I do not bathe myself at all, but am bathed by someone else (312-115)
16. I use bedpan with assistance (292-114)
17. I have trouble getting shoes, socks, or stockings on (305-057)
18. I do not have control of my bladder (230-124)
19. I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces

20. I spend most of the time partly undressed or in pajamas

21. I do not have control of my bowels

22. I dress myself, but do so very slowly

23. I get dressed only with someone's help

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
THIS GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO IN CARING FOR YOUR HOME OR YARD. CONSIDERING JUST THOSE THINGS THAT YOU DO, PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH

1. I do work around the house only for short periods of time or rest often

2. I am doing less of the regular daily work around the house than I would usually do

3. I am not doing any of the regular daily work around the house that I would usually do

4. I am not doing any of the maintenance or repair work that I would usually do in my home or yard

5. I am not doing any of the shopping that I would usually do

6. I am not doing any of the house cleaning that I would usually do

7. I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry

8. I am not doing any of the clothes washing that I would usually do

9. I am not doing heavy work around the house

10. I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am getting around only within one building
2. I stay within one room
3. I am staying in bed more
4. I am staying in bed most of the time
5. I am not now using public transportation
6. I stay home most of the time
7. I am only going to places with restrooms nearby
8. I am not going into town
9. I stay away from home only for brief periods of time
10. I do not get around in the dark or in unlit places without someone's help

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>I am going out less to visit people (028-044)</td>
</tr>
<tr>
<td>2.</td>
<td>I am not going out to visit people at all (029-101)</td>
</tr>
<tr>
<td>3.</td>
<td>I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help (003-067)</td>
</tr>
<tr>
<td>4.</td>
<td>I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily (015-084)</td>
</tr>
<tr>
<td>5.</td>
<td>I show less affection (007-052)</td>
</tr>
<tr>
<td>6.</td>
<td>I am doing fewer social activities with groups of people (012-036)</td>
</tr>
<tr>
<td>7.</td>
<td>I am cutting down the length of visits with friends (027-043)</td>
</tr>
<tr>
<td>8.</td>
<td>I am avoiding social visits from others (034-080)</td>
</tr>
<tr>
<td>9.</td>
<td>My sexual activity is decreased (039-051)</td>
</tr>
<tr>
<td>10.</td>
<td>I often express concern over what might be happening to my health (018-052)</td>
</tr>
<tr>
<td>11.</td>
<td>I talk less with those around me (002-056)</td>
</tr>
<tr>
<td>12.</td>
<td>I make many demands, for example, insist that people do things for me, tell them how to do things (038-088)</td>
</tr>
<tr>
<td>13.</td>
<td>I stay alone much of the time (023-086)</td>
</tr>
<tr>
<td>14.</td>
<td>I act disagreeable to family members, for example, I act spiteful, I am stubborn (249-088)</td>
</tr>
<tr>
<td>15.</td>
<td>I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them (240-119)</td>
</tr>
<tr>
<td>16.</td>
<td>I isolate myself as much as I can from the rest of the family (237-102)</td>
</tr>
</tbody>
</table>
17. I am paying less attention to the children               (238-064)
18. I refuse contact with family members, for example, turn away from them                      (256-115)
19. I am not doing the things I usually do to take care of my children or family                (242-079)
20. I am not joking with family members as I usually do                                           (255-043)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE  □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I walk shorter distances or stop to rest often

2. I do not walk up or down hills

3. I use stairs only with mechanical support, for example, handrail, cane, crutches

4. I walk up or down stairs only with assistance from someone else

5. I get around in a wheelchair

6. I do not walk at all

7. I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg

8. I walk only with help from someone

9. I go up and down stairs more slowly, for example, one step at a time, stop often

10. I do not use stairs at all

11. I get around only by using a walker, crutches, cane, walls, or furniture

12. I walk more slowly

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I am confused and start several actions at a time</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I have more minor accidents, for example, drop things, trip and fall, bump into things</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I react slowly to things that are said or done</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I do not finish things I start</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I forget a lot, for example, things that happened recently, where I put things, appointments</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I do not keep my attention on any activity for long</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I make more mistakes than usual</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I have difficulty doing activities involving concentration and thinking</td>
<td></td>
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</tbody>
</table>

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE [ ]
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am having trouble writing or typing

2. I communicate mostly by gestures, for example, moving head, pointing, sign language

3. My speech is understood only by a few people who know me well

4. I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly

5. I don't write except to sign my name

6. I carry on a conversation only when very close to the other person or looking at him

7. I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words

8. I am understood with difficulty

9. I do not speak clearly when I am under stress

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐
THE NEXT GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO OTHER THAN MANAGING YOUR HOME. BY THIS WE MEAN ANYTHING THAT YOU REGARD AS WORK THAT YOU DO ON A REGULAR BASIS.

DO YOU USUALLY DO WORK OTHER THAN MANAGING YOUR HOME? 

YES NO

IF YOU ANSWERED YES, GO ON TO THE NEXT PAGE.

IF YOU ANSWERED NO:

ARE YOU RETIRED? 

YES NO

IF YOU ARE RETIRED, WAS YOUR RETIREMENT RELATED TO YOUR HEALTH? 

YES NO

IF YOU ARE NOT RETIRED, BUT ARE NOT WORKING, IS THIS RELATED TO YOUR HEALTH? 

YES NO

NOW SKIP THE NEXT PAGE.
IF YOU ARE NOT WORKING AND IT IS NOT BECAUSE OF YOUR HEALTH, PLEASE SKIP THIS PAGE.

NOW CONSIDER THE WORK YOU DO AND RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (IF TODAY IS A SATURDAY OR SUNDAY OR SOME OTHER DAY THAT YOU WOULD USUALLY HAVE OFF, PLEASE RESPOND AS IF TODAY WERE A WORKING DAY.)

1. I am not working at all _____ (100-361)
   (IF YOU CHECKED THIS STATEMENT, SKIP TO THE NEXT PAGE.)

2. I am doing part of my job at home _____ (094-037)

3. I am not accomplishing as much as usual at work _____ (096-055)

4. I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily _____ (088-080)

5. I am working shorter hours _____ (095-043)

6. I am doing only light work _____ (086-050)

7. I work only for short periods of time or take frequent rests _____ (090-061)

8. I am working at my usual job but with some changes; for example, using different tools or special aids, trading some tasks with other workers _____ (092-034)

9. I do not do my job as carefully and accurately as usual _____ (097-062)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I do my hobbies and recreation for shorter periods of time
   (215-039)

2. I am going out for entertainment less often
   (214-036)

3. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading
   (207-059)

4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading
   (208-084)

5. I am doing more inactive pastimes in place of my other usual activities
   (211-051)

6. I am doing fewer community activities
   (216-033)

7. I am cutting down on some of my usual physical recreation or activities
   (210-043)

8. I am not doing any of my usual physical recreation or activities
   (209-077)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am eating much less than usual
   
2. I feed myself but only by using specially prepared food or utensils
   
3. I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar
   
4. I eat no food at all but am taking fluids
   
5. I just pick or nibble at my food
   
6. I am drinking less fluids
   
7. I feed myself with help from someone else
   
8. I do not feed myself at all, but must be fed
   
9. I am eating no food at all, nutrition is taken through tubes or intravenous fluids

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐
ENGLISH (CANADA)

SF-36

IQOLA SF-36 English (Canada) Acute Version 1.0
SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:
   (circle one)
   Excellent ................................................................. 1
   Very good ................................................................. 2
   Good ....................................................................... 3
   Fair ....................................................................... 4
   Poor ...................................................................... 5

2. Compared to one week ago, how would you rate your health in general now?
   (circle one)
   Much better now than one week ago ................................... 1
   Somewhat better now than one week ago ............................. 2
   About the same as one week ago ...................................... 3
   Somewhat worse now than one week ago ............................. 4
   Much worse now than one week ago .................................. 5

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3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>Yes, Limited A Lot</th>
<th>Yes, Limited A Little</th>
<th>No, Not Limited At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Vigorous activities, such as running, lifting heavy objects, and strenuous sports</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c. Lifting or carrying groceries</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d. Climbing several flights of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Climbing one flight of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Bending, kneeling, or stooping</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Walking more than a kilometer</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>h. Walking several blocks</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Walking one block</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>j. Bathing or dressing yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

4. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>b. Accomplished less than you would like</td>
<td>1</td>
</tr>
<tr>
<td>c. Were limited in the kind of work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>d. Had difficulty performing the work or other activities (for example, it took extra effort)</td>
<td>1</td>
</tr>
</tbody>
</table>

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5. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th>(circle one number on each line)</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. Accomplished less than you would like</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. Didn't do work or other activities as carefully as usual</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

6. During the past week, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one)

Not at all ........................................ 1
Slightly ........................................ 2
Moderately ...................................... 3
Quite a bit ..................................... 4
Extremely ..................................... 5

7. How much bodily pain have you had during the past week?

(circle one)

None ........................................ 1
Very mild .................................... 2
Mild .......................................... 3
Moderate ..................................... 4
Severe ....................................... 5
Very severe .................................. 6
8. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

- Not at all ........................................ 1
- A little bit ...................................... 2
- Moderately ...................................... 3
- Quite a bit ...................................... 4
- Extremely ....................................... 5

9. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week -

(circle one number on each line)

<table>
<thead>
<tr>
<th></th>
<th>All of the Time</th>
<th>Most of the Time</th>
<th>A Good Bit of the Time</th>
<th>Some of the Time</th>
<th>A Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel full of pep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>b. Have you been a very nervous person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>c. Have you felt so down in the dumps that nothing could cheer you up?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>d. Have you felt calm and peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>e. Did you have a lot of energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>f. Have you felt downhearted and blue?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>g. Did you feel worn out?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>h. Have you been a happy person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>i. Did you feel tired?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
10. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (circle one)

- All of the time ........................................... 1
- Most of the time ......................................... 2
- Some of the time ......................................... 3
- A little of the time ....................................... 4
- None of the time ......................................... 5

11. How TRUE or FALSE is each of the following statements for you? (circle one number on each line)

<table>
<thead>
<tr>
<th></th>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don't Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>I seem to get sick a little easier than other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b.</td>
<td>I am as healthy as anybody I know</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c.</td>
<td>I expect my health to get worse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d.</td>
<td>My health is excellent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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CHRONIC RESPIRATORY INDEX QUESTIONNAIRE
First Administration, 7 Point Scale
INTERVIEWER FORM

This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about how short of breath you have been, how tired you have been feeling and how your mood has been.

1. I would like you to think of the activities that you have done during the last 2 weeks that have made you feel short of breath. These should be activities which you do frequently and which are important in your day-to-day life. Please list as many activities as you can that you have done during the last 2 weeks that have made you feel short of breath.

[CIRCLE THE NUMBER ON THE ANSWER SHEET LIST ADJACENT TO EACH ACTIVITY MENTIONED. IF AN ACTIVITY MENTIONED IS NOT ON THE LIST, WRITE IT IN, IN THE RESPONDENT'S OWN WORDS, IN THE SPACE PROVIDED]

Can you think of any other activities you have done during the last 2 weeks that have made you feel short of breath?

[RECORD ADDITIONAL ITEMS]

2. I will now read a list of activities which make some people with lung problems feel short of breath. I will pause after each item long enough for you to tell me if you have felt short of breath doing that activity during the last 2 weeks. If you haven't done the activity during the last 2 weeks, just answer 'NO'. The activities are:

[READ ITEMS, OMITTING THOSE WHICH RESPONDENT HAS VOLUNTEERED SPONTANEOUSLY. PAUSE AFTER EACH ITEM TO GIVE RESPONDENT A CHANCE TO INDICATE WHETHER HE/SHE HAS BEEN SHORT OF BREATH WHILE PERFORMING THAT ACTIVITY DURING THE LAST WEEK. CIRCLE THE NUMBER ADJACENT TO APPROPRIATE ITEMS ON ANSWER SHEET]
1. BEING ANGRY OR UPSET
2. HAVING A BATH OR SHOWER
3. BENDING
4. CARRYING, SUCH AS CARRYING GROCERIES
5. DRESSING
6. EATING
7. GOING FOR A WALK
8. DOING YOUR HOUSEWORK
9. HURRYING
10. MAKING A BED
11. MOPPING OR SCRUBBING THE FLOOR
12. MOVING FURNITURE
13. PLAYING WITH CHILDREN OR GRANDCHILDREN
14. PLAYING SPORTS
15. REACHING OVER YOUR HEAD
16. RUNNING, SUCH AS FOR A BUS
17. SHOPPING
18. WHILE TRYING TO SLEEP
19. TALKING
20. VACUUMING
21. WALKING AROUND YOUR OWN HOME
22. WALKING UPHILL
23. WALKING UPSTAIRS
24. WALKING WITH OTHERS ON LEVEL GROUND
25. PREPARING MEALS

3.a) Of the items which you have listed, which is the most important to you in your day-to-day life? I will read through the items, and when I am finished, I would like you to tell me which is the most important.

[READ THROUGH ALL ITEMS SPONTANEOUSLY Volunteered AND THOSE FROM THE LIST WHICH PATIENT MENTIONED]

Which of these items is most important to you in your day-to-day life?

[List item on response sheet]

b) Of the remaining items, which is the most important to you in your day-to-day life? I will read through the items, and when I am finished, I would like you to tell me which is the most important.

[READ THROUGH REMAINING ITEMS]

Which of these items is most important to you in your day-to-day life?

[List item on response sheet]
c) Of the remaining items, which is most important to you in your day-to-day life?

[LIST ITEM ON RESPONSE SHEET]

d) Of the remaining items, which is the most important to you in your day-to-day life?

[LIST ITEM ON RESPONSE SHEET]

e) Of the remaining items, which is the most important to you in your day-to-day life?

[LIST ITEM ON RESPONSE SHEET]

[FOR ALL SUBSEQUENT QUESTIONS, ENSURE RESPONDENT HAS APPROPRIATE RESPONSE CARD IN FRONT OF THEM BEFORE STARTING QUESTION]

4. I would now like you to describe how much shortness of breath you have experienced during the last 2 weeks while doing the five most important activities you have selected.

a) Please indicate how much shortness of breath you have had during the last 2 weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3a] by choosing one of the following options from the card in front of you: [GREEN CARD]

1. EXTREMELY SHORT OF BREATH
2. VERY SHORT OF BREATH
3. QUITE A BIT SHORT OF BREATH
4. MODERATE SHORTNESS OF BREATH
5. SOME SHORTNESS OF BREATH
6. A LITTLE SHORTNESS OF BREATH
7. NOT AT ALL SHORT OF BREATH

b) Please indicate how much shortness of breath you have had during the last 2 weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3b] by choosing one of the following options from the card in front of you: [GREEN CARD]

1. EXTREMELY SHORT OF BREATH
2. VERY SHORT OF BREATH
3. QUITE A BIT SHORT OF BREATH
4. MODERATE SHORTNESS OF BREATH
5. SOME SHORTNESS OF BREATH
6. A LITTLE SHORTNESS OF BREATH
7. NOT AT ALL SHORT OF BREATH
c) Please indicate how much shortness of breath you have had during the last 2 weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3c] by choosing one of the following options from the card in front of you: [GREEN CARD]

1. EXTREMELY SHORT OF BREATH
2. VERY SHORT OF BREATH
3. QUITE A BIT SHORT OF BREATH
4. MODERATE SHORTNESS OF BREATH
5. SOME SHORTNESS OF BREATH
6. A LITTLE SHORTNESS OF BREATH
7. NOT AT ALL SHORT OF BREATH

d) Please indicate how much shortness of breath you have had during the last 2 weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3d] by choosing one of the following options from the card in front of you: [GREEN CARD]

1. EXTREMELY SHORT OF BREATH
2. VERY SHORT OF BREATH
3. QUITE A BIT SHORT OF BREATH
4. MODERATE SHORTNESS OF BREATH
5. SOME SHORTNESS OF BREATH
6. A LITTLE SHORTNESS OF BREATH
7. NOT AT ALL SHORT OF BREATH

e) Please indicate how much shortness of breath you have had during the last 2 weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3e] by choosing one of the following options from the card in front of you: [GREEN CARD]

1. EXTREMELY SHORT OF BREATH
2. VERY SHORT OF BREATH
3. QUITE A BIT SHORT OF BREATH
4. MODERATE SHORTNESS OF BREATH
5. SOME SHORTNESS OF BREATH
6. A LITTLE SHORTNESS OF BREATH
7. NOT AT ALL SHORT OF BREATH

5. In general, how much of the time during the last 2 weeks have you felt frustrated or impatient? Please indicate how often during the last 2 weeks you have felt frustrated or impatient by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME
6. How often during the past 2 weeks did you have a feeling of fear or panic when you had difficulty getting your breath? Please indicate how often you had a feeling of fear or panic when you had difficulty getting your breath by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME

7. What about fatigue? How tired have you felt over the last 2 weeks? Please indicate how tired you have felt over the last 2 weeks by choosing one of the following options from the card in front of you: [ORANGE CARD]

1. EXTREMELY TIRED
2. VERY TIRED
3. QUITE A BIT OF TIREDNESS
4. MODERATELY TIRED
5. SOMEWHAT TIRED
6. A LITTLE TIRED
7. NOT AT ALL TIRED

8. How often during the last 2 weeks have you felt embarrassed by your coughing or heavy breathing? Please indicate how much of the time you felt embarrassed by your coughing or heavy breathing by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME
9. In the last 2 weeks, how much of the time did you feel very confident and sure that you could deal with your illness? Please indicate how much of the time you felt very confident and sure that you could deal with your illness by choosing one of the following options from the card in front of you: (YELLOW CARD)

1. NONE OF THE TIME
2. A LITTLE OF THE TIME
3. SOME OF THE TIME
4. A GOOD BIT OF THE TIME
5. MOST OF THE TIME
6. ALMOST ALL OF THE TIME
7. ALL OF THE TIME

10. How much energy have you had in the last 2 weeks? Please indicate how much energy you have had by choosing one of the following options from the card in front of you: (PINK CARD)

1. NO ENERGY AT ALL
2. A LITTLE ENERGY
3. SOME ENERGY
4. MODERATELY ENERGETIC
5. QUITE A BIT OF ENERGY
6. VERY ENERGETIC
7. FULL OF ENERGY

11. In general, how much of the time did you feel upset, worried, or depressed during the last 2 weeks? Please indicate how much of the time you felt upset, worried, or depressed during the past 2 weeks by choosing one of the following options from the card in front of you: (BLUE CARD)

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME
12. How often during the last 2 weeks did you feel you had complete control of your breathing problems? Please indicate how often you felt you had complete control of your breathing problems by choosing one of the following options from the card in front of you: [YELLOW CARD]

1. NONE OF THE TIME
2. A LITTLE OF THE TIME
3. SOME OF THE TIME
4. A GOOD BIT OF THE TIME
5. MOST OF THE TIME
6. ALMOST ALL OF THE TIME
7. ALL OF THE TIME

13. How much of the time during the last 2 weeks did you feel relaxed and free of tension? Please indicate how much of the time you felt relaxed and free of tension by choosing one of the following options from the card in front of you: [YELLOW CARD]

1. NONE OF THE TIME
2. A LITTLE OF THE TIME
3. SOME OF THE TIME
4. A GOOD BIT OF THE TIME
5. MOST OF THE TIME
6. ALMOST ALL OF THE TIME
7. ALL OF THE TIME

14. How often during the last 2 weeks have you felt low in energy? Please indicate how often during the last 2 weeks you have felt low in energy by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME
15. In general, how often during the last 2 weeks have you felt discouraged or down in the dumps? Please indicate how often during the last 2 weeks you felt discouraged or down in the dumps by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME

16. How often during the last 2 weeks have you felt worn out or sluggish? Please indicate how much of the time you felt worn out or sluggish by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME

17. How happy, satisfied, or pleased have you been with your personal life during the last 2 weeks? Please indicate how happy, satisfied or pleased you have been by choosing one of the following options from the card in front of you: [GRAY CARD]

1. VERY DISSATISFIED, UNHAPPY MOST OF THE TIME
2. GENERALLY DISSATISFIED, UNHAPPY
3. SOMEWHAT DISSATISFIED, UNHAPPY
4. GENERALLY SATISFIED, PLEASED
5. HAPPY MOST OF THE TIME
6. VERY HAPPY MOST OF THE TIME
7. EXTREMELY HAPPY, COULD NOT HAVE BEEN MORE SATISFIED OR PLEASED
18. How often during the last 2 weeks did you feel upset or scared when you had difficulty getting your breath? Please indicate how often during the past 2 weeks you felt upset or scared when you had difficulty getting your breath by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME

19. In general, how often during the last 2 weeks have you felt restless, tense, or uptight? Please indicate how often you have felt restless, tense, or uptight by choosing one of the following options from the card in front of you: [BLUE CARD]

1. ALL OF THE TIME
2. MOST OF THE TIME
3. A GOOD BIT OF THE TIME
4. SOME OF THE TIME
5. A LITTLE OF THE TIME
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME
CRQ RESPONSE SHEET

1. BEING ANGRY OR UPSET
2. HAVING A BATH OR SHOWER
3. BENDING
4. CARRYING, SUCH AS CARRYING GROCERIES
5. DRESSING
6. EATING
7. GOING FOR A WALK
8. DOING YOUR HOUSEWORK
9. HURRYING
10. MAKING A BED
11. MOPPING OR SCRUBBING THE FLOOR
12. MOVING FURNITURE
13. PLAYING WITH CHILDREN OR GRANDCHILDREN
14. PLAYING SPORTS
15. REACHING OVER YOUR HEAD
16. RUNNING, SUCH AS FOR A BUS
17. SHOPPING
18. WHILE TRYING TO SLEEP
19. TALKING
20. VACUUMING
21. WALKING AROUND YOUR OWN HOME
22. WALKING UPHILL
23. WALKING UPSTAIRS
24. WALKING WITH OTHERS ON LEVEL GROUND
25. PREPARING MEALS

OTHER ACTIVITIES


Activity 3a)
Activity 3b)
Activity 3c)
Activity 3d)
Activity 3e)
You have previously completed a questionnaire(s) telling us about how you were feeling and how your lung disease was affecting your life. This is a follow-up questionnaire designed to find out how you have been getting along the last [insert length of time since last seen].

When you are answering the questions this time I will tell you the answer you gave us the last time. I would like you to give your answer today keeping in mind what you said the last time. For example, let's say that last time I asked you how short of breath you were while beating carpets [GIVE RESPONDENT GREEN CARD] and you said "4 Moderate shortness of breath". If you were exactly the same today, you would answer 4 once again. If you were more short of breath you would choose 1, 2, or 3 and if you were less short of breath you would choose 5, 6, or 7.

[FOR QUESTIONS 4a) to 4e) INSERT ACTIVITIES 3a) to 3e) FROM FIRST ADMINISTRATION ANSWER SHEET]

4. I would now like you to describe how much shortness of breath you have experienced during the last two weeks while doing each of the five most important activities you have selected.

a) Please indicate how much shortness of breath you have had during the last two weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3a] by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [GREEN CARD]

b) Please indicate how much shortness of breath you have had during the last two weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3b] by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [GREEN CARD]
c) Please indicate how much shortness of breath you have had during the last two weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3c] by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [GREEN CARD]

d) Please indicate how much shortness of breath you have had during the last two weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3d] by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [GREEN CARD]

e) Please indicate how much shortness of breath you had during the last two weeks while [INTERVIEWER: INSERT ACTIVITY LISTED IN 3e] by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [GREEN CARD]

5. In general, how much of the time during the last two weeks have you felt frustrated or impatient? Please indicate how often during the last two weeks you have felt frustrated or impatient by choosing one of the following from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

6. How often during the past two weeks did you have a feeling of fear or panic when you had difficulty getting your breath? Please indicate how often you had a feeling of fear or panic when you had difficulty getting your breath by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

7. What about fatigue? How tired have you felt over the last two weeks? Please indicate how tired you have felt over the last two weeks by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [ORANGE CARD]
8. How often during the last two weeks have you felt embarrassed by your coughing or heavy breathing? Please indicate how much of the time you felt embarrassed by your coughing or heaving breathing by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

9. In the last two weeks, how much of the time did you feel very confident and sure that you could deal with your illness? Please indicate how much of the time you felt very confident and sure that you could deal with your illness by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [YELLOW CARD]

10. How much energy have you had in the last two weeks? Please indicate how much by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [PINK CARD]

11. In general, how much of the time did you feel upset, worried or depressed during the last two weeks? Please indicate how much of the time you felt upset, worried, or depressed during the last two weeks by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

12. How often during the last two weeks did you feel you had complete control of your breathing problems? Please indicate how often you felt you had complete control of your breathing problems by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [YELLOW CARD]

13. How much of the time during the past two weeks did you feel relaxed and free of tension? Please indicate how much of the time you felt relaxed and free of tension by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT'S ANSWER FROM PREVIOUS ADMINISTRATION]. [YELLOW CARD]
14. How often during the last two weeks have you felt low in energy? Please indicate how often during the last two weeks you have felt low in energy by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

15. In general, how often during the last two weeks have you felt discouraged or down in the dumps? Please indicate how often during the last two weeks you have felt discouraged or down in the dumps by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

16. How often during the last two weeks have you felt worn out or sluggish? Please indicate how much of the time you felt worn out or sluggish by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

17. How happy, satisfied, or pleased have you been with your personal life during the last two weeks? Please indicate how happy, satisfied or pleased you have been by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [GRAY CARD]

18. How often during the last two weeks did you feel upset or scared when you had difficulty getting your breath? Please indicate how often during the last two weeks you felt upset or scared when you had difficulty getting your breath by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]

19. In general, how often during the last two weeks have you felt restless, tense, or uptight? Please indicate how often you have felt restless, tense, or uptight by choosing one of the following options from the card in front of you, keeping in mind that last time you answered the questionnaire you chose [INSERT PATIENT’S ANSWER FROM PREVIOUS ADMINISTRATION]. [BLUE CARD]
During the Respiratory Rehabilitation phase, you will be required to attend triweekly education and exercise sessions for five weeks, delivered on a group basis. The group sessions will be on such topics as: understanding lung disease, exercise guidelines, breath control, airway clearance, inhaler technique, preventing lung irritation, energy conservation, medications, nutrition, community and personal resources, and stress management. You will also exercise with the group at every session. Individual education sessions will be held as necessary, in order to discuss issues unique to your particular situation. All testing will be repeated at the end of the Respiratory Rehabilitation phase.

After the Respiratory Rehabilitation phase, you may be asked to undergo a one-to-one interview with the research coordinator, Pat Camp, in the privacy of your home or some other mutually agreeable location. If you participate in this interview, you will be asked questions about the Respiratory Rehabilitation program.

**Risks and Benefits**

There are minimal risks associated with the exercise component of this study. However, if you feel that for whatever reason you do not wish to continue with the respiratory rehabilitation sessions and/or the assessments required, you may withdraw from the study at any time, without affecting your medical care. It is unlikely that the participation in this study will have a positive effect on the reversal of your lung disease process. However, participating in the respiratory rehabilitation sessions, improving your fitness level, learning more about COPD and improving your skills in coping with your particular situation may improve your quality of life.

**Length of Study/Time Commitment**

The length of the study is approximately twelve weeks. The total time commitment is approximately 10 - 15 hours, in addition to the time spent in the rehabilitation program. The twelve week study consists of one week of initial assessment; five weeks of usual medical care during the Control phase, five weeks of usual medical care and the education and exercise sessions during the Respiratory Rehabilitation phase; and one week of follow-up testing. If you are selected for the personal interviews, this is a short (1 hour) interview which will be scheduled approximately two weeks after the end of the Respiratory Rehabilitation program.

**Confidentiality of Data**

You will not be identified by name, initials, or patient medical record number in any document produced from this study. Upon agreeing to participate in this study, you will be assigned a subject number. All data collected in this study will refer to the participants by their subject number only. If you are selected to provide a personal interview, the staff at Saint Mary’s will not be informed of your participation in the interview.

**Monetary Compensation**

There is no monetary compensation available for this study.
APPENDIX C
RESPIRATORY REHABILITATION PROGRAM
Saint Mary’s Hospital and Ridge Meadows Hospital

Education Content

Understanding Lung Disease
Breath Control / Inhaler Technique
Preventing Lung Irritation
Medications
Energy Conservation
The Importance of Home Exercise
Nutrition
Airway Clearance
Community and Personal Resources
Stress Without Distress
Stair Climbing

Exercise Content

Warm-up chair exercises led by exercise leader, or by using video
Aerobic exercise: treadmill, bicycle ergometer, arm ergometer, hall walking
Strengthening exercises: light free weights for upper extremity and lower extremity muscle groups (Ridge Meadows Hospital)
GUIDING QUESTIONS FOR THE QUALITATIVE INTERVIEWS

Trigger Question: What was your perception of the program and what changes have you noticed as a result of the program?

Perceptions of the Program:
What was it like?
What did you think about the education classes?
Was the information easy to understand?
What is like, learning in a group environment?
How did you like learning with other people with COPD?
How did you find the classroom? Comfortable, large enough, etc.
Were you comfortable using the exercise equipment?
Did you find the exercise challenging?
How would you describe the people that work at the program?

Changes Noticed:
How did you incorporate the information into your daily life?
Has your opinion of exercise changed?
What changes have you noticed since taking the program?
How is it different when you do your usual activities?
Has your experience of shortness of breath changed? How?

Trigger Question: What were the strengths and weaknesses of the program?
What was it about the program that you liked the most? The least?
What was particularly helpful to you? Why were those things helpful? What was it about the program that made it effective/ineffective?

Trigger Question: What recommendations do you have for the program?
Can you suggest any changes to the exercise/education that would make it more helpful?
Was there anything about the exercise/education that could have been lengthened/shortened?

Final Question:
What other important information have I not asked about? Is there something I have missed that you feel I should know?
CALCULATION OF THE ALPHA LEVEL

Number of questionnaires: 2
Number of components per measure: 2
Total number of measures 4

Number of testing sessions = 3
Number of measures multiplied by number of testing sessions = 12

Experimental alpha level = 0.10
Experimental alpha level divided by total number of measures for study = 0.10 / 12

Test-wise alpha level = 0.01
Test-Retest Reliability Raw Data

SF-36 Physical Summary and Mental Health Summary Scores

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Sickness Impact Profile Physical and Psychosocial Component Summary Scores

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Test Retest Reliability Raw Data continued.

**Chronic Respiratory Questionnaire Physical Function and Emotional Function Scores**

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