CARRYING ON WITH LIVING: THE IMPACT OF PULMONARY REHABILITATION ON THE HEALTH BEHAVIOUR OF OLDER ADULTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

Shirley Price BScOT

A thesis submitted in conformity with the requirements for the degree of Masters of Science

Graduate Department of Rehabilitation Science

& the Collaborative Program in Aging & the Life Course

University of Toronto

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Abstract & Keywords

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Introduction: This study explored the health behaviour of older adults with COPD. Objectives included: 1) to explore the process of successfully managing COPD; 2) to identify health behaviour strategies utilized; 3) to identify factors influencing health behaviour change; 4) to understand the impact of pulmonary rehabilitation (PR). Methods: Eleven community-dwelling older adults were interviewed following PR. Interviews were coded and analyzed using constant comparative analysis, comparing and contrasting incoming data with emerging theory. Findings: Two distinct models were developed representing participants’ experience with COPD and health behaviour change: Struggling with Living: Life with COPD before Pulmonary Rehabilitation; and Carrying on with Living: Life with COPD following Pulmonary Rehabilitation. Conclusions: Older adults with COPD engaged in a limited repertoire of health behaviour strategies which were relatively ineffectual prior to participation in PR. PR had a major impact on health behaviour strategies, and on the external and personal factors influencing health behaviour.

Keywords: chronic obstructive pulmonary disease, older adult, health behaviour change
Acknowledgements

I would like to acknowledge the following faculty members in the Graduate Department of Rehabilitation Science for their support of my research studies:

Cheryl Cott PhD, DipGer, BPT
Thesis Supervisor

Dina Brooks PhD, MSc, BScPT
Bonnie Kirsh PhD, MEd, BScOT
Members, Professional Advisory Committee

I would like to acknowledge the following organizations for their financial assistance in supporting my research study:

Canadian Respiratory Health Professionals Fellowship,
Canadian Lung Association

Ontario Respiratory Care Society Fellowship,
Ontario Lung Association

Employee Bursary Program,
West Park Healthcare Centre
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List of Abbreviations, Symbols, and Nomenclature

*COPD* – chronic obstructive pulmonary disease

*Older adults* – adults aged 55 years and older

*Pulmonary rehabilitation (PR)* – an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities

*Self-management* – skills needed to carry out medical regimens specific to a chronic disease

*ATS* – American Thoracic Society

*FEV*₁; *FVC* – Forced Expiratory Volume in 1 second; Forced Vital Capacity

*MRC* – Medical Research Council Dyspnea Scale

*CSES* – COPD Self-efficacy Scale

*HBM* – Health Belief Model

*TTM* – Transtheoretical Model

*SOC* – Selective Optimization and Compensation
As a clinician, I have been practicing Occupational Therapy for 13 years, the last 10 of which have been with a pulmonary rehabilitation program in an urban rehabilitation centre. A large component of occupational therapy intervention in this program involves teaching regarding preventative health and health behaviour strategies primarily to older adults with Chronic Obstructive Pulmonary Disease (COPD). As a Clinical Practice Leader with the program, I have sought out and implemented best practices in the delivery of occupational therapy services to our patients. I have collaborated with my colleagues to integrate new principles, techniques, theories, and evidence into our practice over the years, including principles of adult learning, models of health behaviour change, and self-management education and action plans. Throughout my time with the pulmonary rehabilitation program, I have seen many patients return to the program for repeat courses of rehabilitation demonstrating varying levels of knowledge or evidence of health behaviour change. From this experience grew my interest in understanding health behaviour change in my patients. A review of the literature left me with questions regarding how older adults with COPD engage in health behaviour change and what are the factors influencing health behaviour. While initially I intended to explore the process by which older adults with COPD incorporate health behaviour change into their daily lives following pulmonary rehabilitation, what I discovered was that the participants in my study were utilizing health behaviour strategies prior to pulmonary rehabilitation, although their repertoire of strategies was small and attempts to manage the disease ineffectual. This thesis represents my research exploring health behaviour change in older adults with COPD and the impact of rehabilitation.
Chapter 1 – Introduction & Literature Review

Chronic Obstructive Pulmonary Disease (COPD) is a respiratory disorder largely caused by smoking, and is characterized by progressive, partially reversible airway obstruction and lung hyperinflation, systemic manifestations, and increasing frequency and severity of exacerbations (O’Donnell et al., 2007). Symptoms of COPD include shortness of breath, cough and sputum production which increase in severity as the disease slowly progresses, imposing activity limitations and reduction in quality of life (Public Health Agency of Canada, 2007).

While 80% to 90% of COPD cases are caused by cigarette smoking, other risk factors include occupational exposure to dusts and some fumes, repeated childhood respiratory tract infections and childhood exposure to second-hand smoke, and a genetic deficiency of alpha-1 antitrypsin, an anti-protease which protects the lung tissue from damage (Public Health Agency of Canada, 2007).

In 2004, COPD was the 4th leading cause of death in both men and women in Canada (up from 5th place in 1999); actual mortality rates, however, are likely underestimated as primary cause of death is often coded as another diagnosis such as congestive heart failure or pneumonia, rather than COPD (O’Donnell et al., 2007). According to a 2005 Canadian Community Health Survey (CCHS), 4.4% of Canadians over the age of 34 years (3.9% of men, 4.8% of women) reported that they had been diagnosed by a health professional with COPD (Public Health Agency of Canada, 2007). These data may also underestimate the actual impact of COPD because it is commonly under recognized and/or under diagnosed (Rabe et al., 2007).
Data show that the proportion of individuals diagnosed with COPD increases with age (see Table 1), thus COPD is a significant health issue for older adults. Indeed, activity restriction, use of homecare services, and hospitalization rates all increase with age, especially for the 75+ years group (Public Health Agency of Canada, 2007).

Table 1. Prevalence of physician-diagnosed COPD, adults aged 35+ years, Canada 2005

<table>
<thead>
<tr>
<th>Age Group (Years)</th>
<th>% Men</th>
<th>% Women</th>
<th>% Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44</td>
<td>1.6</td>
<td>2.5</td>
<td>2.0</td>
</tr>
<tr>
<td>45-54</td>
<td>2.7</td>
<td>4.0</td>
<td>3.4</td>
</tr>
<tr>
<td>55-64</td>
<td>4.1</td>
<td>6.0</td>
<td>5.0</td>
</tr>
<tr>
<td>65-74</td>
<td>6.7</td>
<td>7.2</td>
<td>7.0</td>
</tr>
<tr>
<td>75+</td>
<td>11.8</td>
<td>7.5</td>
<td>9.3</td>
</tr>
<tr>
<td>35+</td>
<td>3.9</td>
<td>4.8</td>
<td>4.4</td>
</tr>
</tbody>
</table>

Adapted from Public Health Agency of Canada, 2007

The importance of the appropriate management of COPD in older adults is emphasized by Ariel and Goldstein (2002) who summarize the following challenges in the management of COPD in the elderly: 1) diagnosis may be overlooked due to inattention or to attribution of the symptoms to other conditions, such as aging, deconditioning, asthma, and cardiac disease; 2) older adults with asthma may be misdiagnosed as having COPD; 3) older adults with COPD receive significantly less home care than patients similarly disabled by neurologic or musculoskeletal conditions; and, 4) older adults discharged from acute care prematurely face an increased risk of early readmission or death. With these challenges and the increasing prevalence in older age, COPD is a significant issue for older adults.

Management of COPD includes smoking cessation, pharmacotherapy (symptom control, vaccination to prevent flu/pneumonia), management of acute exacerbations, pulmonary
rehabilitation, oxygen therapy, and surgery (O’Donnell et al., 2007). Pulmonary rehabilitation is an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities (American Thoracic Society [ATS], 2006), and includes exercise training, self management education, and psychosocial support (O’Donnell et al., 2007). Despite inclusion in the Canadian and other COPD guidelines on behalf of professional societies, pulmonary rehabilitation was accessed by only 1.2% of the COPD population in Canada in 2005 (Brooks et al., 2007). This low level of participation in rehabilitation is alarming considering the challenge of the issue of COPD for our aging population.

Pulmonary rehabilitation has been proven to produce short-term benefits including reduced dyspnea, increased exercise tolerance, and improved health-related quality of life in patients with COPD; the benefits of which have been primarily attributed to the exercise component of rehabilitation (Lacasse, Goldstein, Lasserson, & Martin, 2006). The evidence regarding the effect of post-rehabilitation follow-up programs in sustaining health behaviour change and benefits of pulmonary rehabilitation is not clear. Brooks, Krip, Mangovski-Alzamora, and Goldstein (2002) found that neither conventional nor enhanced follow-up had long-lasting effects (> 1 year). Derom, Marchand, and Troosters (2007) summarized in a review of the literature that follow-up programs seem to be important after shorter programs, because the benefits of an 8-week outpatient program have not been well-maintained with usual care, telephone support or monthly follow-up visits; however, programs lasting 6 months or more were more successful in maintaining the obtained benefits. Bourbeau and Nault (2007), on the other hand, argue that for self-management education to be successful, continuous communication with a case manager following rehabilitation is a necessity.
As a result, experts are recommending the inclusion of self-management education in pulmonary rehabilitation with the aim to yield better and/or prolonged benefits (ATS, 2006; Bourbeau & Nault, 2007; Derom et al., 2007; Effing et al., 2007). While self-management education has been found highly effective in managing chronic illnesses, such as asthma, arthritis, and diabetes (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Worth & Dhein, 2004), the benefit and mechanism of health behaviour change is less well understood in the COPD population.

A recent Cochrane Database Review (Effing et al., 2007) concluded that self-management education for individuals with COPD was clearly associated with improvement in quality of life and a reduction in hospital admissions; but due to heterogeneity in interventions, study populations, follow-up time, and outcome measures, data were still insufficient to formulate clear recommendations regarding the form and contents of self-management education programs.

According to Bourbeau, Nault, and Dang-Tan (2004), self-management applies to any formalized patient education program aimed at teaching skills needed to carry out medical regimens specific to the chronic disease, guide health behaviour change, and provide emotional support for patients to control their disease, where health behaviour change refers to the implementation of healthy lifestyle behaviours and/or skills. The health behaviour strategies considered necessary for successful COPD management are well-documented in the literature. The ATS (2006) provides a comprehensive list of education topics to be covered in self-management education, including breathing strategies, proper use of medications, bronchial hygiene, exercise and physical activity, energy conservation techniques, and prevention and early treatment of exacerbations, to name a few. Bourbeau et
al. (2004) lists health behaviours that include disease-specific skills/strategies (smoking cessation, optimization of medications, identification and response to changes in symptoms, and breathing techniques) as well as general lifestyle behaviours (health eating, physical activity, and utilizing stress management techniques). Few studies have investigated how or why these behaviours are incorporated by individuals with COPD.

Studies to date have evaluated the effect of self-management education on outcomes such as symptoms, exercise tolerance, health-related quality of life, and/or health service utilization. This implies that self-management education results in behaviour change. However, as pointed out by Bourbeau et al. (2004), few studies in COPD have examined if self-management is an effective way to change lifestyle and health behaviour. The authors suggest that further research should focus on health behaviour change interventions in order to design more effective self-management programs. Experts continue to advocate for the inclusion of self-management education in the treatment of COPD, acknowledging that further research is required, and should focus on how self-management education results in health behaviour change (ATS, 2006; Bourbeau et al., 2004; Effing et al., 2007).

Few researchers have attempted to understand health behaviour from the perspective of those living with COPD. Cicutto, Brooks, and Henderson (2004) conducted focus groups to gain insight into the self-care behaviours that individuals with COPD undertake to manage their disease. Several behavioural strategies were used in order to adjust physically and emotionally to their disease including breathing exercises, medications, physical exercise (aerobic and strengthening exercises), self-talk, acceptance of the condition, and laughter. In a follow-up study by the authors (Cicutto & Brooks, 2006), a provincial survey was conducted to identify self-care behaviours used by individuals with COPD in the community.
Barriers to engaging in health behaviours included not knowing about strategies, and not having them recommended. As the survey in this study was community-based, not many of the participants would have had much if any education regarding self-management of COPD.

In another qualitative study by Nault et al. (as cited in Bourbeau et al., 2004, p.276) patients were asked to list which strategies they implemented following a self-management program. The following strategies were adopted by patients: energy conservation principles, use of an action plan with prescription of antibiotics and prednisone, use of pursed-lip breathing techniques, and regular home exercises. Barriers included: natural progression of the disease, and the presence of co-morbid conditions. While all of these studies identified strategies important in COPD management from the individuals’ perspectives, they offered no further understanding of the process involved in changing health behaviour (such as how and/or why individuals adopt health behaviours, and the factors influencing health behaviour change).

Given the focus in the COPD self-management literature on behaviour modification and health behaviour change, a look towards theories/models used to explain health behaviour change is an appropriate next step.

According to Woodard, Mark, and Berry (2001), the theories and/or models that have been studied in relation to health behaviour and exercise more extensively than others and provide the foundation on which many contemporary exercise behaviour interventions are based, include: Bandura’s Social Cognitive Behaviour Theory (Self-Efficacy Theory); the Health Belief Model (HBM); and Prochaska’s Transtheoretical Model and Stages of Change. As exercise should be the mainstay of all pulmonary rehab programs (Lacasse et al., 2006), it
is appropriate to examine these three theories/models in exploring health behaviour change in COPD.

Bandura’s Theory of Self-Efficacy

The basic premise of Bandura’s Theory of Self-efficacy is that engagement in behaviour is dependent on an individual’s expectations about personal mastery and success, where two types of expectations influence behaviour: outcome expectancy, which is the belief that specific behaviours will lead to specific outcomes, and self-efficacy expectancy, which is the conviction that an individual is able to successfully execute the behaviour required to produce the outcome (as cited in Scherer & Shimmel, 1996, p. 262). The likelihood of engagement in behaviour is dependent on the individual’s beliefs regarding outcome expectancies (how important and likely is the outcome) and self-efficacy expectancies (how successfully one can carry out the behaviour).

According to Bandura, expectations about self-efficacy are based on four sources of information: performance accomplishment, which is the learning that occurs through successful personal experiences; vicarious experiences are those in which individuals observe others performing activities successfully; verbal persuasion is used to convince individuals, through discussion, to perform an activity; and emotional and physiological arousal, which when high, can weaken the likelihood of performance of an activity (as cited in Salazar, 1991, p.131). When an individual has strong beliefs that they will be successful in performing an activity (high self-efficacy), they are more likely to attempt it (adopt the behaviour).
The Health Belief Model

The Health Belief Model (HBM) was originally developed in an attempt to understand how people behaved with respect to preventative health behaviours (such as screening for illness and immunizations) and was based on value-expectancy theory, where behaviour is the function of the subjective value of an outcome and of the subjective expectation that a particular action will achieve that outcome (Janz, Champion, & Strecher, 2002). In the context of health behaviour, the desire to get and/or stay healthy (value) is dependent on the belief that a specific health action will improve health (expectation) (Janz et al., 2002). According to the HBM, the likelihood of engaging in health behaviour is dependent on four cognitive components: 1) Perceived susceptibility - one’s belief regarding the risk of a perceived health threat; 2) Perceived severity - one’s belief regarding the seriousness of the perceived health threat; 3) Perceived benefit - one’s belief regarding how effective any action will be in reducing the threat; and 4) Perceived barriers - one’s belief regarding the costs or any negative aspects associated with taking action.

Additionally, the likelihood of taking action is influenced by cues to action - any antecedent event to trigger the behaviour (this includes advice from health professionals, response to symptoms, media campaign) and other variables – modifying factors that may influence the perceived threat of disease (such as sociodemographic factors, personality, knowledge) (Janz & Becker, 1984). The HBM is illustrated in Figure 1 below.
Self-efficacy was a later addition to the model as a fifth independent variable influencing the likelihood of health behaviour being taken up by Rosenstock, Strecher, and Becker, (1988) The authors recognized that behaviours related to managing chronic illness requires more difficult, longer-term, lifestyle change, whereas in early development of the HBM, the health behaviours examined were relatively simple ones in which people did not question their own competence or ability to follow through (i.e. to have a chest x-ray/flu shot, or not) so self-efficacy did not arise as an important variable.

The Transtheoretical Model and Stages of Change

The Transtheoretical Model (TTM) uses stages of change to integrate processes and principles of change from across major theories of intervention by comparing theories of psychotherapy and behaviour change (Prochaska, Redding, & Evers, 2002). The resultant model is one that describes behaviour as a process that unfolds over time through a sequence of stages, and that individuals apply various processes in order to progress through the stages
of behaviour change. The core constructs of TTM include stages of change, decisional balance, self-efficacy, and processes of change (Prochaska et al., 2002). Stages of change refer to discrete phases individuals go through in which specific behaviours are expected. Table 2 outlines the stages of change and provides a description of behaviour at each stage.

Table 2. Stages of Change in the Transtheoretical Model

<table>
<thead>
<tr>
<th>Stage of change</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplation</td>
<td>Has no intention to take action within the next six months</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Intends to take action within the next six months</td>
</tr>
<tr>
<td>Preparation</td>
<td>Intends to take action within the next thirty days and has taken some behavioural steps in this direction</td>
</tr>
<tr>
<td>Action</td>
<td>Has changed overt behaviour for less than six months</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Has changed overt behaviour for more than six months</td>
</tr>
</tbody>
</table>

From Prochaska et al., 2002

In moving through these stages, decisional balance and self-efficacy influence behaviour (that is the weighing of pros and cons to changing, and the confidence that one can engage in healthy behaviours across challenging situations) (Prochaska et al., 2002).

Finally, TTM suggests that individuals utilize different processes of change to help them progress through the various stages, such as consciousness raising (increasing awareness about the causes, consequences, and cures for a particular problem behaviour), self-reevaluation (includes cognitive and affective assessments of one’s image with and without a particular unhealthy habit), and counterconditioning (learning healthier behaviours that can substitute for problem behaviours), to name just a few (Prochaska et al., 2002). The processes of change are illustrated in Table 3 below.
Table 3. Processes of change that mediate progression between the stages of change

<table>
<thead>
<tr>
<th>Stages of Change</th>
<th>Pre-contemplation</th>
<th>Contemplation</th>
<th>Preparation</th>
<th>Action</th>
<th>Maintenance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processes</td>
<td>Consciousness raising</td>
<td>Dramatic Relief</td>
<td>Environmental reevaluation</td>
<td>Self-Reevaluation</td>
<td>Self-Liberation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Counterconditioning</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Helping Relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reinforcement management</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Stimulus control</td>
</tr>
</tbody>
</table>

From Prochaska et al., 2002

The model not only attempts to explain behaviour, but can be used in planning behaviour-related interventions to support individuals to use the processes at their appropriate stage in order help them progress through the stages of behaviour change.

Application of Theories/Models in COPD Health Behaviour Research

Self-efficacy theory is the behaviour theory that has been discussed most commonly in the literature on COPD, and is often measured in this population specifically with respect to symptom control, pulmonary education and rehabilitation, and self-management interventions (Atkins, Kaplan, Timms, Reinsch, & Lofback, 1984; ATS, 2006; Bourbeau et al., 2004; Bourbeau & Nault, 2007; Gormley, Carrieri-Kohlman, Douglas, & Stulbarg, 1993; Kaplan, Ries, Prewitt, & Eakin, 1994; Lemmens, Nieboer, & Huijsman, 2008; Scherer & Shimmel, 1996; Wigal, Creer, & Kotses, 1991). Indeed, the COPD Self-Efficacy Scale (CSES) was developed in 1996 (Wigal, Thomas, & Kotses, 1991) based on the premise that individuals with COPD who experience severe shortness of breath may develop low self-efficacy expectations regarding their ability to manage or to avoid breathing difficulty in certain situations or during certain activities. The intent of the scale was to enable clinicians to identify situations in which individuals with COPD experience low self-efficacy. This
would allow clinicians to target interventions designed to increase self-efficacy, enhancing the individuals’ ability to re-engage in activities. The CSES has been shown to be a valid and reliable tool in this population, and has been used extensively in research on COPD and self-efficacy (Kasikci & Alberto, 2007; Scherer & Schmieder, 1996; Zimmerman, Brown, & Bowman, 1996).

Bourbeau et al. (2004) stressed the importance of self-efficacy in learning and adopting self-management behaviours. The authors presented a simplified model which demonstrated how interventions can be used to increase self-efficacy to result in behaviour change (see Figure 2, below).

![Figure 2. Causal model of behaviour change, from Bourbeau et al., 2004.](image)

In this model, clinicians are encouraged to focus on interventions aimed at increasing patients’ knowledge regarding their disease and its management, and teaching the necessary disease-specific self-management skills in order to increase self-efficacy, which results in behavior change (engagement in self-management behaviour). While intuitive, this model has not yet been empirically tested.

There has been relatively little research on the application of the health belief model in COPD. Schofield, Kerr, and Tolson (2007) utilized the HBM in a qualitative study exploring the smoking behaviours of older adults with COPD. Qualitative interviews were conducted.
asking participants to discuss their beliefs about smoking and its impact on their health. The HBM was then applied in analyzing (coding) the interview data. The study described participants’ smoking-related beliefs as they related to the elements of the HBM (perceived threat, perceived benefits, perceived barriers to/costs of quitting smoking, cues to action, and self-efficacy). They found that almost 60% of the participants continued to smoke even though they perceived smoking as a threat to their health, only one participant articulated any perceived benefit to quitting smoking, and many identified barriers to quitting smoking, such as addiction and lack of family support. In this study, the Health Belief Model was inadequate in explaining health behaviour change.

In an earlier study George, Kong, Thoman, and Stewart (2005) examined health beliefs, experiences, and behaviours as they related to medication adherence. Through content and thematic analysis of in-depth interviews, while they did not apply the HBM directly, the authors identified health beliefs, experiences, and behaviours pertaining to adherence and non-adherence. The identified themes were then used to develop a questionnaire which included statements grouped in the three categories (beliefs, experiences, behaviours). The questionnaire was then distributed to individuals who were involved in respiratory support groups and/or a rehabilitation centre in Australia. Quantitative analysis of the questionnaire results revealed that significant differences in some health beliefs, experiences, and behaviours were observed between COPD patients with high medication adherence, and suboptimal adherence. Specifically, adherent patients had greater understanding about their illness and the options for managing the illness, and greater confidence that their current management would keep their illness under control. On the other hand, there were no significant differences between the adherent and less adherent groups in their perception of
control over illness management. In this study, while some health beliefs were consistent with some behaviours, health behaviour could not be fully explained or predicted based on health beliefs.

Finally, only one study applying the transtheoretical model to COPD could be found. Yang and Chen (2005) examined exercise behaviour in COPD patients from an outpatient program by applying the Transtheoretical Model to identify the stages and processes used to engage in exercise. The authors administered two previously developed questionnaires (the Stages of Exercise Change Questionnaire, and the Processes of Change Questionnaire) and used the data to stratify the patients into five groups (pre-contemplation, contemplation, preparation, action, and maintenance). While 50% of participants were found to be in the maintenance stage of exercise, the model was unable to demonstrate how patients got to that stage or remained in that stage.

There are several limitations to using health behaviour theories in explaining or predicting health behaviour. In general, health behaviour theories are based on the assumption that health is a highly valued goal for most people, and that health behaviour is rational and intentional (Janz & Becker, 1984; Salazar, 1991). They do not address other attitudinal/cultural factors influencing health behaviour (Posse, 2001), such as previous experience with the healthcare system, social and cultural norms regarding attitudes towards health in general, and attitudes towards the role of self and the institution in healthcare. Nor do these theories address the influence of social support and peer pressure (Conner & Norman, 2005). The impact of other socioeconomic and environmental factors (e.g. costs, transportation, availability of programs, weather) on health behaviour is also ignored.
The literature on health behaviour change in COPD to date has primarily focused on the impact of pulmonary rehabilitation, and more recently self-management education, on functional outcomes, health-related quality of life, and healthcare utilization. There has been increasing emphasis on the need to focus research and interventions on behaviour modification and health behaviour change and there has been some recognition of the role of health behaviour theories/models in explaining health behaviour. Little attention has been given to the role of pulmonary rehabilitation and health behaviour change from the perspective of older adults with COPD.

The current study is intended to add to this area of the literature by exploring the health behaviour of older adults with COPD following pulmonary rehabilitation. The study objectives include: 1) to understand the process of learning to successfully manage COPD in this population; 2) to identify health behaviour (self-management) strategies utilized by older adults with COPD; 3) to identify the factors influencing health behaviour change in older adults with COPD; and 4) to understand the impact of pulmonary rehabilitation on the health behaviour of older adults with COPD.
Chapter 2 – Methods

Research Design

A qualitative methodology was chosen for this study, as it aims to gain a thorough understanding of the experience of older adults with COPD with respect to their health behaviours and the meaning and/or role of pulmonary rehabilitation. Qualitative methods are appropriate to this type of research as they are used to “explore substantive areas about which little is known or about which much is known to gain novel understandings”, and to “obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional research methods” (Strauss & Corbin, 1998, p.11). Grounded theory refers to “theory that was derived from data, systematically gathered and analyzed through the research process” (Strauss & Corbin, 1998, p.12). This approach is used to develop theory which explains how “individuals interact, take actions, or engage in a process in response to a phenomenon” (Cresswell, 1998, p.56). A grounded theory approach is well-suited to the nature of the objectives of the current study, which includes understanding how individuals interact, take actions, or engage in health behaviour change in response to living with COPD.

Sample

Theoretical sampling techniques were used to recruit participants for the study. Theoretical sampling refers to a process whereby the “selection of participants is directed by the emerging analysis, and the theory being developed from data is subsequently modified by data obtained from the next participants” (Morse & Richards, 2002, p.68). This allows the researcher to gain further insight into the experiences of the participants, while testing,
altering and confirming developing theoretical propositions. The boundaries of the data collection included community-dwelling older adults who: 1) were medically diagnosed with COPD; 2) were aged 55 years and over, as symptoms of COPD usually do not appear in people younger than age 55 (Public Health Agency of Canada, 2007); 3) had completed a pulmonary rehabilitation program within 3-24 months of the study, as studies show the benefits of PR decline after 6-12 months, while health-related quality of life may be preserved up to two years (ATS, 2006); 4) were living independently in the community; and 5) were able to participate in a one hour interview in English. Potential participants who had prior acquaintance with the researcher, who was an occupational therapist associated with the pulmonary rehabilitation program, were not invited to participate in the study.

Sampling began with individuals who had participated in the pulmonary program on an outpatient basis, and who were also attending a post-rehabilitation maintenance program. This strategy served two main purposes: 1) selecting individuals who were more likely to have similar experiences to compare and contrast would allow for a richer understanding of their experience and inform developing theory; and 2) ensured that the participants were not familiar with the researcher, who had not worked in the outpatient program within the previous two years. The maintenance program consisted of a once to twice weekly visit to the centre which included a check-in with the program nurse and participation in a group exercise session, supervised by a physiotherapist.

As the interviews progressed, and it became clear that the social support provided by the maintenance program was an important factor in influencing participants’ engagement in health behaviour, the selection of participants was then geared towards individuals who did not attend the maintenance program in order to compare and contrast their experiences.
These individuals were recruited through the pulmonary follow-up clinic. This clinic follows patients upon completion of their rehabilitation programs at intervals of 1 month, 6 months, and annually.

Further sampling led to the selection of participants based on a range of categories such as the availability of other types of social support, length of time since completing rehabilitation, and severity of lung disease until theoretical saturation was reached (i.e. no new categories emerged from the data). As the sampling categories were identified by the researcher, these categories were described to the pulmonary program nurse and/or physiotherapist who identified potential participants. Informational letters (appendix A) were then handed out to potential participants by the program nurse or physiotherapist. Interested individuals were given the researcher’s contact information, and/or gave permission to be contacted by the researcher.

Setting

The pulmonary rehabilitation program was set in a large free standing rehabilitation and complex continuing care facility in an urban setting. It was offered as a 6-week inpatient program or a 12-week (3 days/week) outpatient program. In both programs, participants were prescribed an exercise program, supervised and monitored by Physiotherapists, and received comprehensive individual and group education delivered by members of the interdisciplinary team, including Registered Nurses, Respiratory Therapists, Physiotherapists, Occupational Therapists, a Pharmacist, a Registered Dietician, a Psychologist, a Recreation Therapist, and a Social Worker. Education topics covered included respiratory health and disease, self-management principles, breathing control and techniques, bronchial hygiene, medications, health maintenance (including illness prevention and avoidance of irritants),
nutrition, energy conservation principles, stress management and relaxation, leisure and recreation, and community resources.

Data Collection

The purpose of the research study was explained to each potential participant, and a written description of the project was provided, prior to obtaining written consent (appendix B). Information on severity of lung disease, level of disability related to COPD symptoms, and sociodemographic characteristics were collected on all participants in order to describe participants and to drive theoretical sampling. Severity of disease, as measured by Forced Expiratory Volume in 1 second and Forced Vital Capacity (FEV\textsubscript{1}; FVC), was categorized as mild, moderate, or severe (appendix C). This information was collected by the program nurse or physiotherapist (and was measured within 12 months of the interview) and provided to the researcher prior to interviews. Level of disability was measured using the Medical Research Council (MRC) dyspnea scale, used to classify severity of COPD symptoms, ranking level of breathlessness on activity on a scale of 1 – 5 (the higher the score, the higher the level of perceived disability) (O’Donnell, et. al., 2004) (appendix D). The MRC score and sociodemographic characteristics (summarized in appendix E) were ascertained face-to-face by the researcher at the time of the interviews.

Data were collected primarily through semi-structured interviews (30-60 minutes in length). A semi-structured interview guide (appendix F) comprised of 3-4 open-ended questions was followed to gather information from participants regarding how COPD affected their daily lives, how they incorporated strategies to manage their COPD into their day-to-day activities, and any potential barriers and/or enablers to managing their COPD. Probing questions were used, as necessary, to encourage participants to elaborate on their
thoughts, or to more thoroughly explore concepts relevant to emerging theory. As analysis of the interview data progressed, new questions evolved to address emerging theory. In fact, the original study questions set out to explore the process by which participants incorporated health behaviour strategies they learned in pulmonary rehabilitation into their daily lives. As interviews progressed it became clear that prior to rehabilitation, many participants were already making attempts to change health behaviours, but they did not feel successful in managing their disease. In subsequent interviews, participants were asked to reflect on what life was like before and after pulmonary rehabilitation.

Data Analysis

Data analysis procedures for grounded theory methods were used, in consultation with three sources (Chenitz & Swanson, 1986; Cresswell, 1998; Strauss & Corbin, 1998). Analysis proceeded concurrently with data collection. Interviews were audio-taped and transcribed verbatim, and pseudonyms were assigned to protect the identities of participants. Transcripts were then analyzed utilizing coding techniques which included open, axial, and selective coding. Open coding refers to the process whereby data are broken down into concepts and given labels. These concepts were then compared and grouped together based on similar characteristics into categories. “In vivo codes” are labels which are taken directly from the words of the participants (Strauss & Corbin, 1998), and were used to name concepts and categories as much as possible. During the open coding process, a table of codes was developed, used, and modified during the analysis of subsequent interviews. Open codes assigned in the beginning stages of analysis included: limitations, anxiety, symptoms, reducing activities, planning activities, exercise, confidence, control, motivation. Related
open codes were then grouped into categories, such as COPD experience, health behaviour strategies, and personal factors.

As categories were developed, the process of axial coding began. Axial coding refers to the process of relating categories to their subcategories, linking categories at the level of properties and dimensions (Strauss & Corbin, 1998). During this stage, statements were formed to describe how categories relate to each other (i.e. how categories influence each other, under what conditions and/or contexts do particular events occur, etc.). For example, it was evident that the participants’ COPD experience led them to learn and implement health behaviour strategies, and that personal factors directly influenced the uptake of these strategies. Constant comparative analysis was used throughout to compare and contrast incoming data with emerging theory.

The final stage in the process of analysis was selective coding. Selective coding refers to the process of integrating and refining theory (Strauss & Corbin, 1998) and involves forming propositions in order to integrate the relational statements developed during axial coding. After much revision based on examining the relationships among categories, two theoretical models were formed. The first model, Struggling with living: life with COPD before pulmonary rehabilitation, explains the process and factors involved in health behaviour change in this population prior to pulmonary rehabilitation. The second model, Carrying on with living: life with COPD following pulmonary rehabilitation builds on the first model, and demonstrates the profound impact pulmonary rehabilitation had on the process and factors influencing health behaviour change.

Several procedures were used to ensure trustworthiness of the data. In sampling, the maintenance group was first targeted to reduce the chance that participants would be familiar
with the researcher, who worked as a clinician with the inpatient program. As most of the maintenance participants previously attended the outpatient program, they would be less likely to know the researcher, and would then be more likely to be truthful in their responses. Once sampling moved to include individuals from the follow-up clinic, who may have been attended the inpatient program, potential participants who had completed their rehabilitation more recently were selected (after which point the researcher had not been working with the inpatient population). An accurate record of codes was compiled and continuously referred to and verified with as theory emerged during analysis as the interviews progressed. At the end of each interview, field notes were recorded to capture observations and/or reflections regarding the new information and the researcher’s interpretations. Finally, theoretical memos and diagrams were used to document on-going analysis and hypothesizing regarding relationships among categories, which led to further questioning and probing to gain a clearer understanding of the direction of the developing model.
Chapter 3 – Results

In all, eleven participants with moderate to severe COPD who had completed a pulmonary rehabilitation program in the 3-24 months prior to the interview; five of whom were enrolled in a pulmonary maintenance program at the time of the interview. The sample included six men and five women aged 59-78 (average age = 70; median age = 68). All of the participants were past smokers with moderate to severe COPD. Five participants had less than two other health co-morbidities, while six participants had 3-6 other health co-morbidities, such as osteoarthritis, hypertension, and heart disease. Six of the participants were married and living with a spouse; four were separated or widowed and living alone; and one was separated and living with an adult child. On average, participants were moderately limited by shortness of breath (average MRC score of 3 = walks slower than people of the same age on the level or stops for breath while walking at own pace on the level). Finally, three participants used supplemental oxygen. For a complete summary of the demographic characteristics of the participants, see appendix E.

Participants described their experience living with COPD, their attempts to manage their disease, and the meaning of successful disease management in the context of life before and after pulmonary rehabilitation. The results are organized as follows: the first section will present the model of Struggling with living: Life with COPD prior to pulmonary rehabilitation, in which participants described utilizing some health behaviour strategies, the resultant struggle with living they experienced and the external and personal factors influencing this process; the subsequent section will present a second model, Carrying on with living: life with COPD following pulmonary rehabilitation, which represents a more
successful experience consisting of more complex relationships among health behaviour strategies, and the external and personal factors influencing health behaviour change.

**Struggling with living: life with COPD prior to pulmonary rehabilitation**

The model representing participants’ experience living with COPD prior to pulmonary rehabilitation is presented below.

![Diagram](image)

**COPD Experience prior to Pulmonary Rehabilitation**

The COPD experience is represented by the disease characteristics (including disease progression and recurrent exacerbations), limitations, emotional toll including anxiety and depression, a long duration of symptoms, and a general lack of awareness regarding specific management strategies.
Disease Characteristics

Participants described the progressive nature of their disease and the deterioration of their health. While the progression was often slow, the increasing difficulties and uncertainty of the disease induced anxiety and fear in participants.

I guess another thing that concerned me a lot was how is this going to progress and how quickly is it going to progress?... So there was I guess a certain amount of fear but I guess fear of the unknown and then just in general how long I was going to be able to function on my own without assistance (Mr. Q)

In addition, frequent exacerbations interfered with daily life, were quite debilitating, and resulted in further loss of function which was not always fully regained.

Day-to-day life was in some ways more difficult than it is now because it was much scarier. I had four exacerbations and three of them landed me in the hospital. Now that’s pretty scary (Mr. U)

Limitations

In describing life with COPD, participants consistently referred to limitations placed on their daily lives and activities related to symptoms of shortness of breath and fatigue. They experienced difficulties with personal care, such as showering and getting dressed; and household tasks, such as cleaning and vacuuming. Leisure and social activities were often the first to go, such as gardening, and going out with family and friends.

Oh, it was extremely difficult. I felt at times that I just couldn’t do really very much. Simple tasks were often more difficult than I could deal with (Mrs. N)

It was evident that these limitations permeated all aspects of every day life including life roles and relationships. In fact, although most of the participants were past retirement age, six of them had stopped working because of the impact of their symptoms related to COPD. Participants described how the inability to do certain things impacted their roles as grandparents, and changed their relationship with friends and families. Not surprisingly,
participants with a greater number of other health co-morbidities tended to experience more limitations in their daily lives.

In addition to limitations related to the physical symptoms of COPD, some limitations were caused by fear and anxiety. The anticipation of running into problems with breathing or having to use “rescue medications”, particularly in public places, caused participants to avoid going out or place themselves in social situations.

I was either afraid of getting caught short of breath or I didn’t know how to manage my breathing at all or how to get it under control quickly enough to realize that, okay I don’t need 911. So there was a lot of things I basically just stopped doing because of the fact that I was a little bit concerned of not being able to, I guess catch my breath properly (Mr. Q)

Fear and anxiety often had the effect of avoiding activities that might lead to shortness of breath, furthering the limitations imposed on day to day life and participation in life roles.

Emotional Toll

Living with the limitations, anxiety and fear related to living with this chronic illness had an emotional toll. Depression was expressed as a common phenomenon. The isolation brought on by loss of participation in meaningful activities, and not being able to keep up with friends and family was difficult for some. For others, the frustration of not being able to do things the same way they had always done them was too much.

It just makes you depressed at times. So yes, I guess it pretty well sucks…you go to try to do something and you’re really limited. You’re unable to do it. So you sort of feel like you’re kind of useless. At least, that’s how I feel. I feel kind of … sometimes I get really upset with myself and get very emotional (Mrs. B)

It was felt by most participants that it is the enjoyable things in life that “go first” when struggling with day-to-day activities.
**Duration of symptoms**

It was common among participants that they had lived with these limitations and the emotional impact for some years prior to being referred to pulmonary rehabilitation. In fact, most reported that they had been diagnosed with COPD anywhere from 5 to 30 years prior to entering the program; many of them expressing that they had suffered the symptoms long before that.

(I was) diagnosed, I guess, a little over five years ago but going through records after I moved, I found that I’ve been taking the same medication over ten years ago (Mrs. B)

Once diagnosed with COPD, participants were recommended to stop smoking, and prescribed medications. Beyond this, however, participants generally had little understanding of their disease or its management.

I didn’t even know I had it. I went to the hospital, I forget what it was for, for some other reason and the doctor told me, did you know that you have COPD? I told him no, I didn’t know that. What is it? And at any rate, I never did anything about it. I just suffered through it for years. I had the puffers; sometimes they worked, sometimes they didn’t… But as far as informing myself of it, I never did really (Mr. J)

Participants were unaware of other disease management strategies. In fact, for most, pulmonary rehabilitation was not offered until several years later, and usually at the request of the participant, who had heard about it by word of mouth. Only three participants reported learning about pulmonary rehabilitation from their physician soon after diagnosis.

**Health Behaviour Strategies prior to Pulmonary Rehabilitation**

Despite limited knowledge of their disease or its management, participants engaged in some health behaviour strategies. These can be organized under two broad categories: those which aimed to treat/reduce/combat symptoms; and those that promote coping and/or adapting to symptoms.
Strategies to Treat/Reduce/Combat Symptoms

Prior to pulmonary rehabilitation, strategies employed by participants to treat/reduce/combat symptoms included smoking cessation, medication, and some exercise. As part of primary management, smoking cessation and the prescription of medications by the family doctor or a respirologist was the common course of treatment for all participants. And although all participants had been prescribed medications by their physicians, they reported they did not always understand what they were taking, or why. At times, participants felt unsure of the benefit of their medications.

The only thing I got was this Spiriva and that was prescribed by my doctor then. And then I went to (a Respirologist) and he changed it...he took me off that and put me on something else and I don’t know that it helped. He prescribed this one in the purple, Serevent...So that’s once a day and that’s twice a day. I don’t know if it helps or not (Mr. H)

Although some participants were aware that exercise was important in maintaining their health, it typically was not a main part of their disease management prior to pulmonary rehabilitation. Participants described making attempts to exercise or remain active with activities such gardening, shoveling snow, cycling, and walking. In most cases, participants’ efforts were unsuccessful, usually because of difficulties related to shortness of breath.

I tried exercising (before pulmonary rehab). I got weights and I was exercising at home. I’d do maybe half a dozen and I’d be so out of breath because I didn’t understand how to breathe. (Mrs. N)

Participants felt that in the absence of specific instruction or prescription regarding exercise or physical activity, they were unable to implement this strategy successfully on their own.

Strategies to Cope/Adapt to Symptoms

Participants described how they learned to cope and adapt to their limitations through living with the disease and through trial and error. Strategies included planning, modifying,
and reducing their daily activities. Planning involved taking into consideration how they were feeling and anticipating problems which may arise related to their symptoms.

The major thing I learned was to start being more careful about how I planned my time. There was less impulsive activity, there was more, “ok, I have to plan because, who knows, it may snow tomorrow…. I needed to make sure I had my medications, I needed to make sure that I had my doctors’ visits, I had to make sure that I know where people are and how to get in touch with them, just in case. That kind of thing. And how did I learn? I don’t know, that’s just what you did, OK? (Ms. D)

Some participants found ways to modify activities in order to accomplish tasks. For example, breaking down household chores into smaller, more manageable parts, or spreading them over several days, or modifying techniques/ using equipment to reduce workloads.

I just keep trying to think, how can I make it easier? When I came in here I brought my suitcase and I think I showed you that fold-up crate that I had the last time I was in. It folds up like a milk box on wheels. I brought all my stuff in at once, my suitcase, my pills that I had to bring, and my TV. I wheeled it all in at once (Mr. F)

While planning and modifying were seen as strategies to manage symptoms and enable participation in activities, reducing activities tended to be more an outcome of the disease, or a loss imposed by the disease.

well I slowly weaned myself off and within the next two years I basically stopped all snowmobiling and right to the point where this year where I haven’t gone out at all. It’s rough. It’s just not good (Mr. Q)

**External Factors**

External factors represent variables outside of the individual’s control which have a direct impact or influence on the COPD Experience, engagement in health behaviour strategies, and the resultant struggle with living. These included the presence of other health co-morbidities, aspects of the environment, and social supports.
Other Health Co-morbidities

Most of the participants reported multiple other health co-morbidities, except for two participants (Mr. Q – had no co-morbidities; Mrs. M – had only one co-morbidity). Those with 3-6 co-morbidities experienced more limitations in day-to-day activities and complained more often of depression than those with two or fewer co-morbidities. The presence of co-morbidities also influenced health behaviours in that participants were more likely to attempt to exercise if they had fewer than 3 co-morbidities.

Aspects of the Environment

Participants described how various aspects of the environment were problematic for individuals with COPD, making living with COPD more difficult. Physical barriers such as having to open heavy doors, climb stairs, and negotiate curbs with a walking aid can all cause breathlessness and fatigue. This was quite frustrating as it imposed further limitations on participation in activities, particularly getting out in the community.

Going to church is a hard one. Climbing the stairs. They have a lot of stairs and I find that difficult. And once you get inside ... Saturday night there was a lady, and I know she wasn’t near us, that had such strong perfume it just about knocked you out (Mrs. M)

Many participants also reported how poor air quality and severe weather aggravated symptoms. Fumes, perfumes, and scents in the air can trigger respiratory symptoms quite easily.

I can react very quickly to anything in the air... Um, the environment (is out of my control). When I walk down the street there’s nothing I can do about those fumes (Ms. D)

Participants often found themselves at the mercy of the seasons, struggling in the hot, humid days of summer (particularly when smog is an issue) and again on the extremely cold, windy days during winter.
the summertime and the wintertime, both are bad for you, the summertime more so I believe. This summer wasn’t too bad. And wind, also (Mr. I)

All of these environmental issues contributed to imposing limitations, increasing frustration, hampering efforts to engage in health behaviour strategies, and making life a struggle for those with COPD.

Social Support

Social support was an important influence on individuals and their engagement in health behaviour strategies. Support came from family, friends, and the individuals’ family physician/respirologist.

Family Support

Although many of the participants had grown children or other family members, including two of those who lived alone, family support came primarily from spouses, as reported by the participants. Prior to pulmonary rehabilitation, spousal support was mainly in the form of assistance with activities of daily living and influenced individuals’ engagement in health behaviour strategies.

Assistance with activities of daily living was a complex issue. While participants appreciated the help and support, they often expressed difficulty or frustration with accepting the help.

Most often she tries to help me more so than I would care and I’ll try to describe this, which she did do. If I drop something on the floor, like a quarter, you’d swear to god it was a million dollars when I get it. But, ‘I can get it’, or, ‘I’ll tie your shoes for you’. Please, I can tie them. I’ll get them done… but still to this day she tries to do too many things for me, which I appreciate but I sort of feel like I’m being babied. You know what I mean? (Mr. I)

Participants struggled with their desire to remain independent with the practicality of accepting assistance with some activities. However, when this assistance allowed them to
have the energy to do something else of greater importance, it was received more favorably. At the same time, participants who lived with their spouses tended to employ planning and modifying activities as strategies to manage day-to-day life.

**Friends**

Participants who lived alone or with an adult child more often expressed feelings of anxiety or depression and spoke more often of the support received from friends than that of family members compared to those who were living with spouses. They described their friends as being supportive, understanding, and considerate of their needs.

> having supportive friends who are very understanding about it… just in planning when we spend time together. For example, they know that I don’t like crowds… Um, walking slower. Dropping me off and then parking the car. That kind of thing. Just taking my limitations into consideration… (they are) far more empathetic (than my family) (Ms. D)

It seemed these qualities were important, and in the absence of family members who would be expected to fulfil these needs, these participants sought this type of support in friends. In contrast, those participants who had good family supports described friends as valuable for helping out with tasks or socializing.

> I go to a coffee shop. I spend three hours there and have two cups of coffee. So again, it’s more the social aspect of it. It’s the same people all the time. We sit and talk and talk about what? Who knows? Who cares? Just talk, just like we do here. It’s just being with people. I just like being with people (Mr. I)

**Relationship with Family Physician/Respirologist**

Another relationship of interest, impacting on an individual’s health behaviour is that between the individual with COPD and their physician. Participants acknowledged the expertise of their physicians and stressed the importance of their role in diagnosing, treating, advising, and educating regarding COPD. At the same time, the relationship with the
physician was viewed as a collaborative one, where both the doctor and the individual have a role to play.

The importance of the doctor’s role of course is to be correct in his diagnosis and his recommendation for treatment. That’s about as far as a doctor can go. Of course the communication is very, very important. Dr. J ... I can’t remember his last name...He’s terrific. That man is terrific in communicating... He’s just an open guy that is interested in what he’s doing and understands what he’s doing. He works with the patient. He worked with me so much this last time (Mr. U)

While physicians were responsible for the overall medical care of their patients, they had little control over whether a patient chose to take the advice given, and/or follow through with a treatment plan which required action on the part of the patient, i.e. implement health behaviour change. It is reasonable to presume/postulate that a positive relationship with ones’ physician would have a favorable effect on health behaviour. This was indeed the case found in this study. Participants who described their physicians as supportive, communicative, encouraging, and non-judgmental tended to be more engaged in behaviours to maintain/improve their health.

And then I have a very good GP...she kept encouraging me, she didn’t judge me, she just kept encouraging me, saying, you know, “you shouldn’t be doing this, you should try this” and eventually, we struck a happy medium where I got the right medications and then I started making an effort... It took me a long time to get me to that point, because most of the doctors I had just basically sloughed it off (Ms. D)

This positive relationship fostered health behaviour change by empowering the individual to take ownership over their disease management. Encouragement and support provided the motivation and confidence that the individual was able to make a difference in their health.

Interestingly, the participant who seemed to be struggling the most with successfully managing his health also had a poor relationship with his physician.
He’s the kind of guy that told me, if you don’t want to take it, find yourself another doctor. You can’t discuss anything with him…his word is final and that’s it. So I do a lot of things that I don’t tell him about…I found out in place of statins I can take and to lower cholesterol I can take niacin… now I’ve discovered niacin, so far everything is fine. There’s other ways. And he thinks everything is okay. I just don’t tell him what’s going on (Mr. J)

Not only does this poor relationship result in engagement in fewer health behaviour strategies, but it may lead to potentially dangerous behaviour. Taking medications without the doctor’s knowledge may lead to unforeseen consequences due to drug interactions or side effects. While this may be an extreme response to a lack of communication in the doctor-patient relationship, communication is important in fostering and/or encouraging engagement in healthy behaviours.

**Personal Factors**

Personal factors are aspects/characteristics of the individual that have an impact on the individuals’ COPD experience and their engagement in health behaviour strategies. Prior to pulmonary rehabilitation personal factors included self-direction and sense of control.

**Self-Direction**

Several participants spoke of their efforts to learn more about their disease, to ask questions and become more involved in managing their COPD rather than be passive recipients in their healthcare.

I’m a great one for asking questions. I like to find out just what’s going on because I found out that that’s what helped me. One of the things that helped me the most when I learned about my disease and everything, before I learned was very, very difficult because I didn’t know why all these things were happening. And once you learn to ask questions, it makes it much easier (Mrs. M)

Many patients did not know a lot about their disease, initially. It was often only after they had come through the rehab program that they felt they had learned anything about COPD.
Prior to pulmonary rehabilitation, these self-directed participants learned about their disease by asking their physician/respirologist questions, reading pamphlets and books, contacting the Lung Association, and searching the internet.

Those who exhibited some self-direction tended to be those who were more anxious and/or had experienced more frequent exacerbations, and had fewer other health co-morbidities. The anxiety and exacerbations may well have been motivation to do some investigation regarding the disease. Those who were self-directed were more likely to attempt health behaviour strategies such as controlling their weight and exercise.

**Sense of Control**

A sense of control was something that was, for the most part, lacking in participants prior to pulmonary rehabilitation. They expressed that they had little understanding and no control over their disease prior to pulmonary rehabilitation, particularly related to their breathing difficulties and recurrent exacerbations.

> When you weaken you’re not in control. It (COPD) controls you. When you get a chest infection you are not in control in any way. It just takes over your body and you just fight for relief (Mrs. M)

This lack of sense of control may have contributed to participants’ not attempting to change their health behaviour. It also seemed to be related to feelings of anxiety and depression, although it is not clear which came first.

**Struggling with Living**

The main result of the process involved in living with COPD and attempts to manage the disease was that participants were Struggling with Living. Everyday life centred on what participants were “not able to do”, and it was felt that life in general was difficult before entering the pulmonary rehabilitation program.
Day to day life was mostly watching TV if I wasn’t in bed, and getting my meals, that was about it… I couldn’t breathe. I had trouble walking. Before I come here I couldn’t even walk a quarter block (Mr. F)

The limitations and emotional impact of the disease described by participants were not greatly improved by participants’ efforts to employ health behaviour strategies. Before entering pulmonary rehabilitation, participants relied on a small repertoire of health behaviour strategies to help them manage the disease. And although they quit smoking, were taking the medications prescribed by their physicians, and some had started planning, modifying, and reducing their activities, they felt they were struggling to survive.

You’re limited as to what you can do… You know, simple jobs that become very difficult to do. Life itself becomes difficult with COPD. The more you try to do, the more difficult it becomes… Even going shopping with my wife is difficult, going around the store (Mr. I)

Those who struggled most were those with more other health co-morbidities, more expressed limitations, anxiety and depression, those who retired because of health reasons rather than age, and those with greater perceived disability (MRC=4). Those who were slightly better off in terms of managing with COPD were those with fewer other health co-morbidities, those who lived with their spouse, and those with slightly less perceived disability (MRC=3 on average).

The model described in this section illustrates the course of the individuals’ COPD experience related to engagement in health behaviour strategies and the external and personal factors influencing health behaviour change prior to pulmonary rehabilitation. Regardless of the relative influence of all the factors described, the consistent story told by all participants was one of struggling with living.

The next section will describe how this experience changed for participants with the introduction and participation in pulmonary rehabilitation.
Carrying on with living: life with COPD following pulmonary rehabilitation

The introduction of pulmonary rehabilitation was an important event in the lives of all participants. Pulmonary rehabilitation was the primary source of education and training in health behaviour strategies aimed at COPD management for all. It provided a new context in which all aspects of the model were touched by pulmonary rehabilitation. It had the effect of altering the COPD experience, and impacting both external and personal factors in a way that promoted a more complex interaction among them and health behaviour change. A new model building on the original emerged demonstrating the factors influencing health behaviour change following pulmonary rehabilitation. The resultant model depicts a new view of living with COPD. Rather than Struggling with Living, following pulmonary rehabilitation older adults with COPD found themselves Carrying on with Living. The following model represents this new experience. The bold print represents areas impacted by pulmonary rehabilitation.
**COPD Experience following Pulmonary Rehabilitation**

Pulmonary rehabilitation altered the COPD Experience by impacting the disease characteristics, limitations, and awareness of disease management. Participants reported that their physical decline had slowed and that they experienced fewer exacerbations following participation in the rehab program.

"since I started coming here, touch wood, I haven’t been to the hospital once. And when I graduated from my six week course upstairs, I felt freer because before, honest to goodness, I felt like I wasn’t going to live until tomorrow. And not being able to breath is scary, terrible (Mr. J)"

In addition to decreased symptoms, participants reported an increase in physical strength and abilities, in effect reducing the number of limitations imposed by the disease on day-to-day activities.
I’m so much stronger. Like I’ve done things that I haven’t done in years. A couple of weeks ago I decided I’m feeling good today, I’m making pickles. And I made relishes and beets and pickled a lot of stuff and did different things. In the last six months I’ve made a queen-sized quilt by hand. I’m now making a children’s one and I have way more energy than I’ve had in a long, long time (Mrs. M)

Pulmonary rehabilitation raised awareness for participants regarding disease management strategies [most notably for those who had reported feelings of anxiety and depression, and those with more perceived disability (MRC=4)]. Participants were impressed with the range of skills and strategies they learned in the program. They expressed being completely unaware there was so much they could do to manage their disease.

In fact, I was very skeptical going into the program. I said to my husband what can they do for me, you know? I was really amazed at what they actually did (Mrs. N)

While more specific health behaviour strategies will be discussed in the next section, the impact and importance of pulmonary rehabilitation in providing education and awareness to participants is stressed here. Participants expressed that they would not have achieved the same level of awareness regarding managing their COPD without the pulmonary rehabilitation program.

I still say that what I’ve learned, more than three-quarters of what I’ve learned has come from (pulmonary rehab)… I figure if I hadn’t come here I would have died years ago really because I did not know how to take care of myself. So it has made a huge difference (Mrs. M)

**Health Behaviours learned in Pulmonary Rehabilitation**

Health behaviour strategies learned in pulmonary rehabilitation built on and added to the repertoire of strategies participants had known prior to the program. In continuing with the three broad categories of health behaviour strategies introduced earlier (treating/combating/reducing symptoms, coping/adapting to symptoms, and promoting
healthy lifestyle habits), the health behaviours learned in pulmonary rehabilitation are described here.

Strategies to Treat/Combat/Reduce Symptoms

Pulmonary rehabilitation provided education and training in strategies to treat/combat/reduce symptoms of COPD. Although all participants had quit smoking and were taking medications for COPD prior to pulmonary rehabilitation, they learned more about their medications, including how to take them properly in the program. In addition, participants learned breathing techniques and were prescribed exercise programs.

Participants felt that the breathing techniques had the most significant impact on quality of life and ability to participate in daily activities.

most important is the pursed-lip breathing and actually, that technique has changed my life. I couldn’t walk upstairs. I used to go halfway up and sit and then go the rest of the way. Now, I can go all the way up with the pursed-lip breathing…Even now, the littlest things, if I just stop, sit or stand quiet and do a little bit of pursed-lip breathing, without anybody really noticing what you’re doing you can bring yourself around to continue what you’re doing (Mrs. N)

Once participants were started on an exercise program in pulmonary rehab, participants were unanimous in their belief that exercise was very important in maintaining their health.

(What is most important?) Your exercise, your exercise, your exercise. I believe you have to build yourself up (Mrs. B)

They worked hard at continuing to exercise following the program in various ways such as purchasing equipment to exercise at home, joining a health club or participating in the respiratory maintenance program at the rehabilitation centre. Some participants followed a very strict/rigorous routine, whereas others took a more flexible approach in increasing their level of activity and walking as often as they could. Either way, it was clear that exercise had become part of life for participants following pulmonary rehabilitation.
Strategies to Cope/Adapt to Symptoms

Strategies taught in pulmonary rehabilitation that focus on coping/adapting to symptoms include: energy conservation strategies such as planning, modifying, reducing activities, pacing, using assistive devices, assistance from others, and awareness of and respect for physical limitations.

Planning, modifying activities, and pacing were key strategies participants found that they learned in the pulmonary rehabilitation program. Although some participants had started to plan or modify activities prior to pulmonary rehabilitation, they learned to apply these strategies more efficiently and more generally to day-to-day activities. For others, this was new learning.

I feel I’ve learned many, many coping skills, many, that now it’s become sort of everyday stuff. I don’t really think of it before I do it. Like how to do your laundry and getting things off the shelves. I felt if they could teach me how to do housework, how to keep my house, I could adapt it to any other thing. Which is what I did. They taught me here about doing my housework and everything and it has helped in other ways. Pacing yourself was a really big thing (Mrs. M)

The use of assistive devices and assistance from others were strategies that received less enthusiasm, and tended to be used reluctantly, if only at first. Two assistive devices used by participants included a rollator (wheeled walking aid), used by three participants, and supplemental oxygen which was used by six participants. One participant, in particular, struggled with having to use the rollator, seeing it as limiting what he was able to do.

I’m trapped with the rollator although the arthritis has a lot to do with that too. And I absolutely detest that machine. I don’t like people opening doors for me. I don’t like getting preferential treatment. I don’t like having to use it. I don’t like to be seen using it… I even have it when I’m preparing my meals; I have to do it sitting in the rollator… I have to prepare all my meals sitting. I can only stand for a short time but basically it bothers me most when I’m out (Mr. J)
The same participant, did however, admit that the rollator allows him to get out of his apartment.

I do it (use the rollator) but I hate it, that’s all. I do what I have to do but I have to just bite my tongue and do it. Otherwise I’d be trapped in my apartment watching TV which I am too much of the time as it is (Mr. J)

By the same token, after some initial hesitation, most participants referred to their assistive devices as tools to enable them to participate in daily activities.

I’m using a rollator now and I’m using oxygen. I didn’t do that five years ago…And once you’re on oxygen therapy, you’ll be using a rollator for sure, absolutely. I used it before I was on full-time therapy. I used a rollator because it helped me. So I think by getting on a rollator a year before you’re on full-time oxygen is not unusual and I think it should be encouraged. Because it encourages walking (Mr. U)

Similarly, participants had mixed feelings about asking for or receiving assistance from others. However, while they do not want to ask for assistance, a certain level of acceptance seems to come over time.

And I guess when you’re always very, very independent and you do everything on your own and not ask for much help, I mean it’s very fulfilling in ways but you do have to eventually get over the hump of not being afraid or embarrassed to ask for help. And now I’m not. I don’t hesitate to, you know, if I need something lifted I don’t hesitate to ask my neighbour. I don’t hesitate to call my kids. It’s also due to the fact that I do know that there are some things I just shouldn’t do (Mr. Q)

Another participant expressed an open-mind towards accepting assistance by creating or describing the advantage of inter-dependence.

You help somebody and another time they might help you, don’t matter if it’s a stranger or what. You never know when you’re going to run into trouble and need help. Even with good health you could run into something. If I can do anything for them I do it for them. The same token, so it’s the way you present yourself. If you’re willing to help somebody else they’re willing to help you and at the time I wasn’t well so I just called and they were there (Mr. F)
In this way, he felt better about asking for help because he felt he was also able to give back to others.

Through the pulmonary rehabilitation program, participants felt they learned to be more aware and respectful of their limits. They came to recognize the benefit of not over-exerting themselves, causing worsening of symptoms.

That’s, I think, something that they also taught us out there, was to not to try to go beyond. You should recognize when you can run into problems. So I’m trying to do that (Mr. H)

*Healthy Lifestyle Habits*

Finally, strategies aimed at promoting a healthy lifestyle included: healthy eating/weight control, and illness prevention (hand hygiene, early treatment of exacerbation, etc). While a few participants had been advised prior to pulmonary rehabilitation regarding the benefit of healthy eating/weight control, it was not until they went through the program that they understood how to work towards this goal.

Like in nutrition eating a little bit more proper, proper portions, and eating consistently is very, very important. Even though I still wasn’t eating my three square meals a day prior to it, (pulmonary rehabilitation) made me also realize though that with proper nutrition and proper meals comes a little easier weight control (Mr. Q)

One of the more important strategies taught that had an impact on decreasing exacerbations was that of good hand hygiene practices.

when I go in stores, before I go back home I use a cleanser and clean my hands which I never used to. But I do clean my hands often when I’m outside and I try not to touch too many things. If somebody is behind me coughing (at church), I will not stay put, which before I would have. I just move. I won’t shake hands in church and I told the priest. He sticks out his hand. I said look I’m not shaking your hand. You shake everybody’s hand and then you stick it out to shake mine (Mrs. M)
In addition, participants described an increased awareness regarding catching signs of illness and seeking treatment early to help decrease exacerbations.

In general, carrying on with living was successful to a greater degree for those participants who utilized the breathing control techniques, incorporated exercise into their daily lives, planned and/or paced their activities, and were aware and respected their limitations. Participants perceived these health behaviours as being most important in carrying on with living.

With the addition of pulmonary rehabilitation and a more comprehensive repertoire of health behaviour strategies, a more complex model emerged that incorporated additional external and personal factors influencing the process of health behaviour change than those described earlier.

**External Factors**

With a greater repertoire of health behaviour strategies, the external factors of other health co-morbidities, aspects of the environment, and social support, had more broad influences on the process of health behaviour change. Additionally, the presence of other life demands became more relevant.

**Other Health Co-morbidities**

Although the impact of other health co-morbidities on the COPD experience was described earlier, in this new model, health co-morbidities had a more complex influence on health behaviour change. For some, the presence of co-morbidities made it more difficult to engage in health behaviours aimed at improving their health related to COPD. For others, living with other health co-morbidities may have been beneficial.
In general, participants with 3-6 co-morbidities tended to rely on modifying activities as a health behaviour strategy. While those with fewer than three co-morbidities focused more on exercise and weight control. Those with fewer co-morbidities were, in general, less limited in their physical activity, and more able to participate in exercise.

When other health co-morbidities impacted on the participants’ ability to engage in physical activity, as in osteoarthritis, participants expressed that this interfered with their ability to exercise and/or lose weight.

\[
\text{when my COPD isn’t bothering me, my back is…except for meal times and maybe short trips for shopping and that, I spend most of the time flat on my back. And I’m gaining weight and I don’t like that… But through inactivity, the weight just comes on and in the past 18 months I think, I’ve gained well over 50 pounds and I don’t like it. I’ve been to nutritionists and everything but nobody can help. They all say I’m doing everything right all I’ve got to do is move, which I can’t do (Mr. J)}
\]

Similarly, participants described interference in keeping up with physical activity from osteoporosis, and Crohn’s disease.

Some behavioural strategies aimed at improving health with COPD were common to those recommended for other conditions. In this way, having other health co-morbidities was of benefit to learning health behaviour change, as they had already been practiced by individuals for many years.

\[
\text{Hypertension, um…yeah, just learning to stop myself from getting so upset about things, calm myself down. Because obviously it does affect my breathing as well (Ms. D)}
\]

Ms. D had learned stress reduction and relaxation techniques in pulmonary rehabilitation which she had been familiar with from previous practice related to her history of high blood pressure.
In summary, the impact of other health co-morbidities on engagement in health behaviour strategies for COPD varies and would benefit from further study.

*Aspects of the Environment*

Environmental factors continued to have an important influence on engagement in health behaviour strategies following pulmonary rehabilitation. Keeping physically active and participation in exercise was particularly impacted by environmental challenges. One participant described looking for an appropriate place to do his exercise.

> (when) I lived in the condo I’d do my exercise upstairs and then I’d go down to the treadmill. But I don’t have a treadmill now (that I’m in a house) so this fall I’m going to see about joining, it’s called the Rec-Plex up there, and they’ve got all the weight machines and bikes and treadmills. I’ve got to go and check it out (Mr. F)

For many, availability, location, transportation, and costs can be barriers for individuals looking for a place to do exercise. While the barriers of cost and location may be overcome by finding a local mall, or other public place, the barriers of weather and air quality issues are not so easily resolved. Participants were often deterred from doing any exercise outdoors in the winter because of cold, snow, and wind, and again in the summer because of hot, humid days, particularly when smog was an issue. Overall, participants felt that the most considerable environmental barrier impacting their ability to engage in health behaviour and to carry on with living was that of severe weather.

*Social Support*

Social support also continued to have a tremendous influence on individuals, their health behaviours, and their ability to carry on with living. Spousal support again was important in impacting health behaviour change. With the addition of pulmonary rehabilitation, a whole
new type of support was found in the health professionals and peers associated with the program.

**Family Support**

Spousal support became increasingly influential in how participants engaged in health behaviour change through positive reinforcement and encouragement. This came in a variety of forms, such as receiving “accolades” from a spouse regarding weight loss, reminders and encouragement to keep up with exercise programs, and even doing the exercises together.

she would never let me fail. No, she’s not that bad. If she thought I didn’t do (my exercises), she’d wonder why I wasn’t doing them. Plus she does them with me too quite a few times. Most mornings she does them with me…I would suggest that for any household that the partner should do it with them because it’s an experience together. It’s another thing you can do together (Mr. U)

Through this kind of support, participants found the motivation to take care of themselves, to follow through with their exercises or diet, and enjoy the companionship of their spouse at the same time. While most participants engaged in a variety of health behaviours, those who lived with spouses tended to plan and modify activities more often than those living alone, who tended to reduce activities.

The importance of the support spouses provide was highlighted by one participant who, despite having a supportive family which included a parent and children, stated:

It would be great I guess if I had maybe a little bit more support. Okay, so if I had a partner that was, you know, hey do your exercises. Did you do your exercises today? You know what I mean, like somebody to kind of harp on you like a mother would (Mr. Q)

**Health Professionals with the Pulmonary Rehabilitation Program**

Health professionals associated with the pulmonary rehabilitation and maintenance program offered a great deal of support in helping participants to learn and engage in the behavioural strategies taught in the program. Participants described the role of the health
professionals as providing expertise and guidance, supervision, and encouragement through their positive attitudes.

Participants felt confident that the therapists had some knowledge and training that put them in a position to help them to improve their health.

I think they’ve got a dual purpose there. I mean their expertise in being able to guide you through, but not only that, the (patients) are in a situation where some of them don’t want to accept the fact that they’ve really got a problem and some are so afraid to venture out. There is a safe environment that if they do go beyond, they’ll certainly adapt because they’re with professionals (Mrs. C)

Intuitively, having confidence in the education and guidance provided should have a positive effect on the likelihood of the uptake of the information and subsequent attempt to change behaviour. It also fosters a trust in what is being learned.

Participants also described how the staff provided supervision and correction over their behaviour to ensure strategies were being performed correctly and/or effectively.

I know why I’m doing what I’m doing and I know when to do it. It’s because we did it with the physios in a group. Well, we did our exercises individually and they constantly worked with us. If you weren’t doing it right, they corrected you so it was several months of practicing these techniques. It’s just not somebody telling you (Mrs. N)

Having the opportunity to receive feedback from the “experts” provides some positive reinforcement to solidify performance/behaviour, again, making sustainability of the desired behaviour more likely.

And finally, and what was emphasized most frequently by participants was the impact the positive attitudes of the staff had on their participation in the program.

Yeah, and the staff is absolutely fantastic… the fact that they’re so positive makes you just as positive I think and they don’t look on the down side of anything (Mr. J)
The cheerful, caring personalities of the staff was the most commonly mentioned aspect of the staff of the pulmonary rehabilitation program. This seemed to have the effect of putting participants at ease, and motivating them to engage in learning and practicing what was being taught to them. It also made them feel comfortable to raise concerns and issues, and possibly be more open about their problems, as illustrated by one participant:

Well, they’ve always got time to listen to you. If you’ve got a question they’ll listen to you. There’s smiles on their faces. They like to see you (Mr. F)

Peer Support

In addition to the support received from the staff of the pulmonary rehabilitation program, there was a great deal of discussion regarding the support of peers met through rehab and/or participation in the pulmonary maintenance program. Five of the participants were attending the maintenance program at the time of the interviews and they all felt very strongly about the positive influence of peer support. In fact, participants who were in maintenance, who lived alone, and who had more other health co-morbidities relied more often on peer support than other participants. Participants expressed many advantages to going through rehab with others who have the same diagnosis, including the benefits of a common understanding, shared problem-solving, being able to compare oneself to others, and developing social relationships.

There was a benefit and comfort to learning with others who face similar challenges as there was a common understanding felt among peers. It enabled participants to feel open to discuss their challenges in a non-threatening and non-judgmental environment.

When something happens to you that hasn’t happened to anyone else in your immediate group, it’s very difficult to share because they don’t have that same understanding. When you’re with somebody who has experienced the same thing, it’s a comfort level of just being able to know that somebody understands, really understands (Mrs. N)
According to participants, this common understanding is something that can not be found in relationships with families, friends, or anyone who does not have the same experiences.

It’s different from being with your family. Your family and so on they say they understand but you know they don’t really. Whereas these people you know they do. If you tell them something they’ve already been through it. They know exactly what you’re going through. So in that sense you do feel more comfortable about your illness (Mrs. M)

This common understanding also leads people to feel that they are not alone in the challenges they face.

To be around people who have the same thing as you so that you don’t feel so centred, you’re not centred out… we have a support group here and if you have things that really bother you, it doesn’t matter what it is, you always have someone to speak to and go over everything and they give you a different aspect of the situation or they try to help you in any way they can (Mrs. B)

Participants also found that they learned a lot from one another through problem-solving together. There was benefit to sharing experiences and discussing barriers, challenges, and solutions to living with COPD. This included strategies to manage everyday issues, advice from physicians, and new information found on managing COPD.

And we share stories. And if somebody’s on new medication or something, they’ll mention it or if they’ve heard something or seen something on the net, they’ll bring a printout to tell us about it (Mrs. M)

Participants spoke about the benefit of comparing themselves to others, both while in pulmonary rehabilitation, and in continuing to incorporate health behaviour strategies following rehabilitation.

I remember talking to the other guys that were on my floor, and we were saying, do you think this is really going to help at all, just treadelling your feet kind of thing. But, there was another fellow, he has since died but when he came in, he came in before me, he couldn’t walk without oxygen or a rollator and he was in here about 18 weeks, but when he left, he could walk for an hour without the oxygen and without the rollator. And he encouraged me to stay (Mr. J)
Seeing what others with similar struggles can overcome and accomplish can be very motivating and result in better commitment to health behaviour change. The feeling that “if he can do it, I can do it”. At the same time, seeing others who are in worse condition than oneself can motivate one to initiate health behaviour change in order to avoid getting into that condition.

Sure some of the guys can’t walk 10 feet without having oxygen. A lot of them said they would like to be as good as I am right now when they leave. It’ll never happen to a lot of them because they are beyond that stage. But everybody was trying and everybody was positive (Mr. H)

Finally, the social part of exercising and learning with peers made it all the more likely for participants to engage in health behaviour strategies during and following rehabilitation.

I was very fortunate to have it turn out to be a nice group of people in the group that I felt that we were very supportive of one another. That we would make jokes and have a good time. When I say a good time, like we fumbled through it we knew it. And the other person knew you didn’t and they could make a joke. You know you could take it. I think it made a world of difference (Mrs. C)

Without this type of peer support and socialization, individuals with COPD often become isolated, as they do not feel as comfortable around people who do not understand the disease.

Indeed, one participant who did not participate in the maintenance program after rehab acknowledged the benefit of having someone to exercise with.

And you know the exercise, the fact that we all exercised (in pulmonary rehab), made it easier. Doing it on my own is a pain…Oh I think the support (peer group) would be nice to have. I don’t…it would be nice to have a group environment where you could (exercise)...But everybody being involved and you could see how other people were doing and everything else. That helped (Mr. H)

Other Life demands

Another factor that arose for participants following pulmonary rehabilitation as a potential barrier or enabler to health behaviour change is the challenge of balancing taking care of
oneself with other life demands. This became more relevant following pulmonary rehabilitation due to the larger repertoire of health behaviour strategies. Participants reported that many of the strategies used to manage COPD, beyond smoking cessation and taking medications, take a significant amount of time to perform. Regular exercise, daily breathing exercises, employment of energy conservation strategies, etcetera all take time to do.

Well, you know, when you do start adding up all the time that you need to continue with your life aside from doing your exercises or this and that, I very quickly did realize that – okay, yeah, breathing exercises and one exercise per day is most adequate. You know because by the time you do the rest of your chores, your life chores, I guess, that does soak up a lot and a big part of your day (Mr. Q)

Participants described the difficulty they experienced balancing the time it took to do their exercises and pace themselves with other day-to-day commitments including household tasks, grocery shopping, medical appointments for themselves or spouses, and socializing with friends and family. One participant noted:

it was a bit of a challenge. And that was another thing (I was told), that it would take you a month or six weeks until you get into the regular routine to do what you’re doing, so that you get into a routine. Even now I find sometimes my breathing exercises don’t get done until 10 o’clock in the morning instead of right after breakfast sometime, depending on things. The other day when I didn’t do anything I had to go to the dental hygienist, an early appointment. So that screwed everything up (Mr. H)

Several participants remarked on the difficulty they had had maintaining healthy behaviours while still working. In fact, one participant had been through the rehabilitation program about five years earlier, while still working, and found it very difficult to keep up with health behaviour strategies.

Whenever I started feeling bad I quit working. And the other thing was the first time that I was (in pulmonary rehab), I would go and I wouldn’t do the exercises as I should (because I was still trying to work). And I realized the regiment of the exercise is so important (Mr. U)
Several participants reported that retirement allowed them the advantage of time. They found that in retirement, they could put their health regimen first and take the time required to pace themselves with their activities, perform their daily breathing and other exercises, and plan activities around their exercises. One participant described the impact of having time on her health and well-being.

(time allows me) to be in less in a rush. And if I’m not in a rush, and if I’m not anxious about being in a certain place in a certain time, I’ve got more time to do it. And it just lowers my level of anxiety and therefore my breathing is better (Ms. D)

While most participants perceived time as being on their side in retirement, it is important to recognize time management as a skill that may need to be taught. Having the time to engage in health behaviours is very important to successfully managing chronic illness. As COPD is primarily seen in the older adult population, this could be an advantage; however, it is important not to underestimate the amount of time required, or the need to learn time management skills as part of COPD management.

**Personal Factors**

With the introduction of pulmonary rehabilitation, four new categories emerged regarding the influence of personal factors on engagement in health behaviour change in COPD. They included self-determination, personal motivation, confidence and control, and outlook and perceptions.

**Self-Determination**

Participants expressed self-determination as the most important factor influencing their engagement in health behaviour change. Self-determination built on the concept of self-direction from the earlier model, and encompassed personal responsibility, self-discipline/self-control, and challenging oneself.
It was very clear that following pulmonary rehabilitation participants felt a level of personal responsibility for their own health and health behaviours.

Well if the patient doesn’t put his role or her role forward, doesn’t put it and follow instruction and be part of the solution, it isn’t going to work. The patient’s role is very, very, very important… I think some people just think – oh well, my attendance here (pulmonary rehab) is good enough and it’s going to fix me (Mr. U)

This sense of responsibility came from an increased knowledge of health behaviour strategies, as well as from a place of increased self-awareness. Participants realized that only they knew what their limitations were, and how they were feeling on any given day. This allowed them to know what they were and weren’t capable of, and gave them the power to make decisions for themselves regarding how to manage their disease, and what they needed to do to manage their disease.

Participants also expressed self-discipline or self-control as being key to engaging in health behaviours. They felt that the pulmonary rehabilitation program equipped them with the knowledge and skills to take care of their health, and in implementing the health behaviour strategies was a matter of self-discipline.

You have to be your own disciplinarian but you’ve got to keep that, as the English would say, stiff upper lip. You’ve got to do it. And another cliché, certainly no one else is going to do it for you (Mrs. C)

In addition to exercising self-discipline and self-control, some participants spoke about challenging themselves as a way to motivate or push themselves into action, with respect to engaging in health behaviour. Whether it was exercise, eating healthily and losing weight, or striving to be independent in daily activities, participants reported that a healthy dose of “challenge” could make all the difference. Goal-setting was one strategy used by one participant, Mr. F, to challenge himself.
Well, everybody likes chips and cheesies and stuff. I would set a goal and maybe have it once a week. Or, I like my popcorn, so I’d eat popcorn or chips or cheesies once a week… I just do it on my own (Mr. F)

Confidence and Control

Pulmonary rehabilitation gave participants the confidence and sense of control over their disease to engage in health behaviour change in order to overcome and/or manage the limitations imposed by COPD. It was evident that this confidence and sense of control came from the education provided by the program.

from teaching me to believe that I could do it, not just telling me by the physio, but doing it. You know, as you say, observing firsthand that gee, this works and I can do this. That’s basically what you get or at least what I got out of the program, the fact that I have the ability to control this somewhat. I can’t change it but I can cope with it, work with it and I can do things (Mrs. N)

Participants felt confident in their ability to manage symptoms and participate in day-to-day activities by utilizing strategies learned in the program.

certainly rehab has helped me in that respect, I’ve learned more self-confidence, I can go a little farther afield (Ms. D)

This allowed participants to continue carrying on with living and further motivated them to engage in health behaviour strategies to remain healthy and active.

A sense of control over the disease was further developed because participants felt that what they were doing made a difference. This in itself provided positive reinforcement to engaging in health behaviour change.

I found that it really worked. If you try something and it doesn’t work, well, then it sort of puts you off but if you continue because with practice…when you learn how to do the breathing properly, you have a better feeling in yourself, actually. You have a better feeling and then it just grows on you, I guess and you just do it because then it becomes habit and it’s just something to do that you know is good for you (Mrs. B)
Participants also described engaging in health behaviour when they felt better afterwards. This was especially true for strategies such as exercise, eating healthy to control weight, and taking the time to utilize proper breathing control and pacing.

I know that that will be beneficial to my breathing (to lose weight). I know that that will help. Once I lost the first seven pounds I went back to the doctor. Wow, he says, look what you’ve done. It made me feel good and that gave me the incentive to go and do it more (Mr. I)

For the most part, when participants felt that their ability to manage their disease was within their control, they felt less anxious or depressed, were more likely to engage in health behaviours and were more successful in their objective to carry on with living.

**Personal Motivation**

While self-determination drove health behaviour change for some participants, others defined their own personal motivation to engage in health behaviour strategies. Although personal motivation was a common theme among the participants, the only thing common about it was that the motivation was very personal and individual. Participants expressed the need to find their own personal motivation to encourage engagement in health behaviour strategies. For some it was staying healthy for grandchildren, for others it was staying healthy to continue with desired activities such as volunteer work. One participant explained that she used fear of her disease as a motivator. While another explained finding his motivation in the follow-up visits at the rehabilitation centre:

I have a blue book with all the instructions in it and that’s wherever I am, it is. The commitment, I think that I went there for six weeks and if I don’t do it then I waste it. So that’s what keeps me going... And not only that but I got the feeling that they keep pretty darn close track of what we’re up to... I would like to do better the next time I go for a recheck (Mr. H)

Participants who felt the need to find some personal motivation to engage in health behaviour change were those who more often experienced anxiety or depression, and with few
exceptions had more other health co-morbidities. This seemed to be related to the likelihood that anxiety, depression and other health co-morbidities interfered with the inner drive associated with self-determination.

**Outlook and Perceptions**

The majority of participants expressed a positive outlook following pulmonary rehabilitation. This was conveyed in different ways. Participants were able to view “the bright side” of living with COPD, focusing on their accomplishments and abilities rather than on their limitations; recognizing that “things could be worse”; and viewing assistive devices or help from others as strategies to enable participation in day-to-day activities rather than barriers.

I also had to learn to I guess still be kind of proud of what I do accomplish even though it might have taken me an extra hour, an extra couple of minutes, or even an extra day or two (Mr. Q)

A positive outlook had many beneficial effects on engagement in health behaviour change, including providing the motivation to take action for ones’ health.

(a positive outlook) makes you want to go on. It makes you want to do your very best to keep yourself healthy (Mrs. B)

This attitude led to open-mindedness with respect to learning new health behaviour strategies. It led some participants to embrace their assistive devices or accept help from others. It motivated participants to engage in health behaviour strategies that would help them to manage their symptoms and participate in carrying on with living. For some participants, a positive outlook helped them to find ways to learn to cope with COPD by accepting that while they have a chronic illness they could still improve their quality of life.

(it’s) the acceptance of your limitations and being able to find means of getting around this, not just sitting back and saying woe is me…I was ready and willing to accept the fact that I need to learn how to do this that they were about to
show me because I’m not doing it too well on my own obviously. And then once you’re shown, accept the fact that this is your limit or you’re within your limit (Mrs. C)

In addition to a positive outlook, optimistic perceptions of health and disability seemed to be related to success in carrying on with living (enjoying life):

I don’t consider myself disabled, not really. I just have something that just keeps me back a little bit (Mrs. B)

If you think you’re ill, you feel ill, and it makes you ill. And we’re not ill. We do have a disease but the rest of our body is fine (Mrs. M)

This mind over matter style of thinking was more commonplace among participants following pulmonary rehabilitation than before. Prior to the program, participants saw themselves as sick and not able to do things. They viewed themselves as restricted because of their disease, and felt they could not do anything to improve their situation. One participant articulated how her thinking changed because of pulmonary rehabilitation:

You know you’re having a bad time and ordinarily you’d think well, I really can’t do anything. (After pulmonary rehabilitation) you don’t think that way anymore. You think okay, it’s time for a rest and we’ll get back to this later (Mrs. N)

Participants who had a positive outlook or optimistic perceptions of their health expressed a higher degree of satisfaction with their level of participation in life activities, and had fewer complaints of depression/anxiety. Interestingly, severity of limitations in physical function did not seem related to positive outlook. Indeed, some of the most positive remarks were made by participants who rated themselves as more severely limited by shortness of breath (i.e. MRC=4; stops for breath after walking 100 yards). Pulmonary rehabilitation had a major impact on emotional health and quality of life, regardless of the amount of physical improvement made through rehabilitation.
Carrying on with Living

The most important impact of pulmonary rehabilitation on this model of health behaviour change is the result of *Carrying on with Living*. Despite the expressed limitations, frustrations, and difficulty of life with COPD, following pulmonary rehabilitation a positive outlook was held by a majority of the participants towards continued participation in everyday life and activities, learning to live with the limitations imposed by COPD in a way satisfactory to the individual while taking some degree of control over the disease. *Carrying on with Living* encompassed incorporating COPD into their lifestyle, doing, and enjoying life.

Participants took what they had learned living with COPD and the pulmonary rehabilitation program to develop a lifestyle that incorporated the limitations imposed by COPD, the health behaviour strategies aimed towards its management, and their day-to-day activities in order to go on with life. This was made possible by the understanding that COPD, as a chronic disease, could not be cured; but that the individual could take control over the disease, rather than be controlled by the disease, by engaging in health behaviours and participating in desired activities of daily living.

It’s (COPD) not going to go away. That this is the way it is. This is your lifestyle. This is the way it’s going to be and work with it, don’t fight it. And do everything you can to make it as pleasant (Mrs. C)

Another important aspect of carrying on with living was doing. For many participants, carrying on with living meant focusing on the things they are still “able to do” and “can do”. This included anything from performing everyday chores around the house, going shopping or running errands, to pursuing leisure interests, volunteer work, or going out and being with family or friends.
But I can do dishes and I can cook and I can write and I can look up things on the computer and I can handle the channel changer and I drive the car the odd time. I don’t drive much in the wintertime though because my wife’s a good driver so I don’t need to drive. And we go out. We go visiting relatives. But there’s a lot of things naturally we can’t do. We can’t dance. Although I do. I’ve been to two or three dances but I don’t dance. But (my wife) likes to go and she enjoys dancing and we have a lot of friends there. So we go out to a dance (Mr. U)

Prior to pulmonary rehabilitation, participants focused very much on what they were unable to do because of COPD. However, armed with strategies to manage symptoms, increased physical strength, and a sense of control over their disease, participants felt better able to do the things they wanted to do in life.

Other participants who still found themselves somewhat limited in their physical abilities focused on the things they “want to do”, rather than their limitations.

I’m looking forward to doing things that I’d only thought maybe I might be able to do. We started doing some traveling and it’s become so much easier (Mrs. N)

Interestingly, those who focused on “able to do” and “can do” were those individuals who lived with a spouse, had fewer than three other health co-morbidities, and were on supplemental oxygen; while those who focused on “want to do” were those individuals who lived alone or with an adult child, had 3-6 other health co-morbidities, and had more perceived disability (MRC=4). This speaks to the importance of social supports and level of physical disability in influencing participants’ abilities to engage in activities of daily living. However, regardless of the amount of improvement in physical abilities made in the pulmonary rehabilitation program, there was a consistently positive attitude by all participants, with a focus on “doing”. In fact, although the “want to do” participants were more physically limited in their daily activities, they were not any more focused on their limitations than their “able to do” counterparts.
Finally, for the most part, participants felt that despite their disease, they were able to enjoy life with COPD. Again, this was very much the case, even for those participants who had fewer social supports, more co-morbidities, and more perceived disability.

I just basically started enjoying things that I haven’t enjoyed for years. You know just simply getting out more. Just even walking more. Just generally a little better and of course with a little bit of a better lifestyle it goes all the way around (Mr. Q)

The model of *carrying on with living* illustrates the significant impact of pulmonary rehabilitation on the *COPD experience, health behaviour strategies*, and the external and *personal factors* influencing the health behaviour of older adults with COPD. Despite varying outcomes achieved from pulmonary rehabilitation with respect to physical abilities, symptom control, and quality of life, participants consistently described the impact of pulmonary rehabilitation as enabling them to carry on with living, with a lifestyle characterized by doing and enjoying life.
Chapter 4 – Discussion

This qualitative study explored the health behaviours of older adults with COPD. Two models were developed to reflect the process of health behaviour change in older adults with COPD in relation to participants’ experience living with their disease before and after participation in pulmonary rehabilitation. They were Struggling with living: life with COPD prior to pulmonary rehabilitation; and Carrying on with living: life with COPD following pulmonary rehabilitation. Findings from this study indicate that although older adults with moderate to severe COPD engage in health behaviour strategies prior to pulmonary rehabilitation, their repertoire of strategies is rather limited, as is the success of their attempts to manage their disease. For the most part, these individuals are struggling with living with COPD on a day-to-day basis. Pulmonary rehabilitation had a profound impact on health behaviour and the experience of living with COPD. Following participation in the program these older adults reported implementing a wider range of health behaviour strategies, resulting in carrying on with living. This more successful implementation of health behaviour change is a direct effect of the pulmonary rehabilitation program and its impact on the personal and external factors influencing health behaviour.

Some of the key concepts identified in the current study are similar to previous findings by Cicutto et al. (2004). In their qualitative study identifying self-care issues of individuals with COPD using focus groups, Surviving COPD was a major theme and was achieved through adjusting physically and emotionally to their condition. In addition to utilizing disease management strategies, participants identified that they shifted from active to sedentary lifestyles, reduced activities, planned and paced activities, and balanced living life
with disease management; and they identified the importance of social supports and their emotional health as important in helping their adjustment to their disease. The current study adds dimension to these findings in exploring participants’ experience in the context of pre-and post-pulmonary rehabilitation, highlighting the impact of pulmonary rehabilitation on health behaviour. The current study also explored in greater depth the factors (personal and external) influencing health behaviour change and the effect of pulmonary rehabilitation on these influences.

One of the key impacts of pulmonary rehabilitation found in the current study was the education and awareness provided regarding the wide range of health behaviour strategies directed toward COPD management. Prior to pulmonary rehabilitation, some health behaviour strategies were learned either through advice from a primary physician or through the experience of living with COPD. A substantial amount of learning health behaviour strategies came about through participation in pulmonary rehabilitation. While smoking cessation and medications were prescribed by physicians, participants reported the health behaviours most important in managing COPD included breathing control, exercise, planning and pacing strategies, and awareness and respect of limitations. All of these strategies were primarily learned in the pulmonary rehabilitation program.

The fact that pulmonary rehabilitation was a major source of learning health behaviour strategies addresses two significant barriers to COPD self-management reported in the literature: not knowing about the activity; or not having it recommended (Cicutto & Brooks, 2006). Indeed, Cicutto and Brooks (2006) found from a survey of individuals with COPD in Ontario that only 20% of their participants had ever attended a pulmonary rehabilitation program. While this number is actually quite high compared to the national average of 1.2%,
it is reflective of the fact that just over 1/3 of the pulmonary rehabilitation programs in Canada are in Ontario (24 out of an identified 60 programs) (Brooks et al., 2007). This represents an important barrier for individuals living with COPD. Without access to pulmonary rehabilitation, individuals are missing out on a vital source of education with respect to learning the necessary health behaviour strategies to live successfully with COPD.

This study found that pulmonary rehabilitation had an impact in altering the COPD experience from the perspective of the individuals with the disease. Participants expressed that they had increased physical strength and abilities and fewer exacerbations. This effect is consistent with evidence that pulmonary rehabilitation results in reduced dyspnea, and improved exercise capacity and health-related quality of life (Lacasse et al., 2006) and that self-management education results in reduced hospital admissions (Effing et al., 2007). This lends support to the benefit of pulmonary rehabilitation from the perspective of the individuals who have completed rehabilitation.

Another key impact of pulmonary rehabilitation found in this study was the effect it had on personal factors such as self-determination and confidence and control. Pulmonary rehabilitation provided patients with the knowledge and skills in disease-specific and lifestyle behaviours important in COPD management. Participants felt that this knowledge put the responsibility for their health in their own hands. They felt that through pulmonary rehabilitation, they understood the impact, severity, and consequences of their disease, and they had the knowledge of the benefits of engaging in health behaviours taught in the program. This seems to have had a positive impact on health behaviour change. This thinking is consistent with the constructs of the Health Belief Model (Janz et al., 2002), in which the likelihood of engaging in health behaviour is related to the perceived susceptibility
to or severity of the disease and results when the perceived benefits outweigh the perceived barriers to taking action.

In addition, pulmonary rehabilitation provided the opportunity for participants to learn and practice health behaviours in a supervised and supportive environment. This allowed participants to develop confidence in their abilities to engage in health behaviours and feel more control over their disease. These findings are consistent with Self-Efficacy Theory, in which feelings of mastery predict engagement in health behaviour (Scherer & Shimmel, 1996). In this example, participants were more likely to utilize breathing control techniques or keep up with an exercise regime when they felt their efforts would be successful and when their efforts resulted in decreased shortness of breath.

The current study, however, illustrates the short-comings of both of these theories of health behaviour change, in that health behaviour was not fully explained based solely on participants’ beliefs about their health, the benefits/consequences of engaging in health behaviours, and/or their feelings of self-efficacy. Indeed, other variables related to the COPD experience (described above) and external factors played a role in influencing health behaviour change.

Perhaps one of the most important impacts of pulmonary rehabilitation was the social support provided by the health professionals and peers associated with the rehab and maintenance programs. At least two of the five participants who did not go to maintenance referred to the follow-up program as having a major influence in assisting them to sustain their health behaviour strategies, particularly their exercise program. Those who did attend the maintenance program tended to live alone, have a greater number of other health co-morbidities, and a higher MRC score (greater perceived disability). These participants
accredited their continued engagement in health behaviours to the support of the maintenance program, which included supervision and guidance from the staff, peer support from other participants, and a safe and healthy environment in which to perform their regular exercises. While the mechanism of the support provided by follow-up and maintenance programs is not fully understood, they clearly have some benefit to some individuals with COPD. It may be reasonable to presume that individuals who have fewer social supports and a greater level of disability may be the ones who benefit most from longer pulmonary rehabilitation programs, more closely supervised follow-up, or participation in maintenance programs to sustain benefits from pulmonary rehabilitation and engagement in health behaviours.

It is important to note that participants did engage in some health behaviours beyond physician recommended smoking cessation and medications prior to pulmonary rehabilitation. While the repertoire of health behaviours was generally small, individuals did report engaging in strategies such as planning, modifying and reducing activities in order to cope with their symptoms. This type of behaviour is consistent with previous research on adaptation to chronic illness. Baltes and Baltes’s theory of selective optimization with compensation (SOC) (as cited in Gignac, Cott, & Badley, 2000) describes three adaptational processes: selection refers to avoiding or restricting activities related to a loss of function or capacity (for example, participants reported reducing their activities due to shortness of breath); optimization refers to efforts individuals make to augment or enrich one’s reserves in order to preserve function (e.g. planning activities and pacing oneself in order to preserve energy and/or breath to do normal activities); and compensation includes efforts to meet goals by new means in order to continue with functioning (e.g. some participants used tools to assist in housecleaning and other tasks).
While most participants in the current study reported behaviour consistent with selection, it was unclear why participants differed in their adaptational processes (i.e. some participants used optimization and compensation, as well, while most did not), although it seemed those most limited also reported anxiety and depression. Indeed, during pulmonary rehabilitation participants were formally instructed on the use of strategies that included optimization (e.g. exercise, breathing control) and compensation (e.g. use of a rollator, shower chair), and reported a engaging in a wider range of health behaviours following the program. While there has been research applying SOC to older adults with osteoarthritis to explain behaviour (Gignac et al., 2000; Gignac, Cott, & Badley, 2002) there has not been any work done in this area with the COPD population.

While participants in the current study expressed anxiety and depression as common emotions prior to pulmonary rehabilitation, the impact that these emotions had on health behaviour change can only be inferred. Participants who described experiencing anxiety and depression tended to be those who lived alone, had more other health co-morbidities, were less inclined to utilize health behaviour strategies prior to pulmonary rehabilitation, and tended to rely on finding motivation rather than on self-determination to engage in health behaviour strategies. In carrying on with living, these individuals were more likely to focus on enjoying life and what they wanted to do, rather than what they were able to do. Clearly anxiety and depression influence health behaviour change, but this study did not set out to determine causal relationships. These findings are supported by similar results from a study on the importance of psychological factors on adjustment to COPD which found that higher levels of catastrophic withdrawal coping strategies and lower levels of self-efficacy of symptom management were associated with higher levels of depression, anxiety, and a
reduced quality of life; higher levels of positive social support were linked to lower levels of depression and anxiety; and higher levels of negative social support were linked to higher levels of depression and anxiety (McCathie, Spence, & Tate, 2002).

What we do know from the literature is that while exact prevalence rates are difficult to ascertain due to a number of methodological issues (e.g. variety of outcome measures being used, varying definitions of anxiety and depression from reports of “symptoms” to “disorders”, and small sample sizes) anxiety has been reported in 10-50% of individuals with COPD (Dowson, Kuijer, & Mulder, 2004), and depressive symptoms have been reported in up to 45% of individuals with moderate to severe COPD (ATS, 2006). Dowson, Town, Frampton, and Mulder (2004) summarize the effect of panic and depression on health behaviour as follows: *panickers* will be more motivated than non-panickers to learn new health information but when in a perceived dangerous situation (e.g. severe exacerbation) catastrophic thoughts will inhibit appropriate behaviours; and *depressed patients* more frequently report negative health perceptions, hopelessness, indecisiveness and decreased self-confidence often accompanied by slowed thinking, all of which may decrease motivation to learn and act on vital health information. While the exercise component of pulmonary rehabilitation has been shown to improve psychological outcomes in COPD (Emery, Shermer, Hauck, Hsiao, & MacIntyre, 2003; Trappenburg et al., 2005), COPD guidelines continue to recommend that pulmonary rehabilitation programs include psychosocial interventions specifically to address issues of anxiety and depression (ATS, 2006; Derom et al., 2007).

Another factor that had perhaps the most important influence on health behaviour change before and after pulmonary rehabilitation was that of social support provided by family;
particularly by a spouse. The participants in the current study described support from their spouses in terms of helping with everyday activities, providing emotional support and encouragement, and even partnering in engaging in health behaviours (e.g. exercising together). Participants who lived with their spouses tended to express a more positive outlook, were more successful in implementing behavioural strategies (before and after pulmonary rehabilitation), and perceived themselves as more able than those who lived alone. They tended to be older (70 + years), have fewer other health co-morbidities and were less likely to participate in the maintenance program. The positive relationship between family support and health behaviour is consistent with other findings in the literature. Xiaolian et al. (2002) found a statistically significant positive relationship between family support and self-care behaviour among Chinese adults with COPD from an outpatient pulmonary clinic of a large medical centre; and Kasikci and Alberto (2007) found similar results, with statistically significant relationships between family support and self-care behaviours and between family support and self-efficacy.

There were several limitations of the current study, most of which were related to the sample. The fact that the study sample was small and homogenous is not a limitation in itself, as the intent was not to generalize the results, but to gain a deeper understanding of an the experiences of a group of older adults with COPD. However, due to the fact that the sample was comprised of Caucasian Canadians of European descent (e.g. English, Irish, Welsh), the models resulting from this study do not address cultural influences on health behaviour. On a positive note, based on observation, the sample seemed to be representative of those who attend the pulmonary rehabilitation program at this urban rehabilitation centre. This in itself raises an interesting question regarding who accesses pulmonary rehabilitation,
and whether individuals from various cultural groups are afforded the same opportunities to access appropriate services. Further research in this area is needed.

A final limitation with respect to the sample was that while steps were taken to ensure that the participants were not personally familiar with the researcher, who is a clinician within the rehabilitation program, participants were aware that the researcher was associated with the program and may have recounted their experience with pulmonary rehabilitation more favorably.

With respect to the interview methodology, it is difficult to know how accurate participants’ responses were regarding how they were managing living with COPD and their engagement in health behaviour prior to pulmonary rehabilitation, as this relied on participants’ memories of what life was like before the program. To reduce the impact of this effect, participants were selected based on how long ago they had completed rehab (< 6 months; 6 months < 1 year; 1 < 2 years; and = 2 years). The only way to completely avoid this issue would be to study participants longitudinally, which is a time-consuming effort.

The models presented in this study identified the factors which influenced health behaviour change in a group of older adults with COPD before and after participation in pulmonary rehabilitation. They demonstrated relationships among constructs, but did not determine causation. As such, the models should be applied with this in mind.
Chapter 5 – Conclusion, Practice Implications, & Future Directions

Conclusion

The models presented in this qualitative study illustrate the experience of older adults with moderate to severe COPD and the process involved in living with COPD and learning health behaviour strategies to cope with the disease before and after pulmonary rehabilitation. Both models demonstrate the important influence of personal and external factors on health behaviour change. The result of this process prior to pulmonary rehabilitation was struggling with living. Pulmonary rehabilitation was influential in altering the COPD experience, enhancing social support systems, and improving personal efficacy and coping resources. This led to a very different experience for participants, one of carrying on with living following pulmonary rehabilitation.

Practice implications

This qualitative study supports the evidence recommending pulmonary rehabilitation for individuals with COPD. It describes the health behaviour strategies important to COPD management from the perspective of those living with the disease. The model Carrying on with Living: life with COPD following pulmonary rehabilitation provides a useful framework for explaining the factors influencing behaviour change in older adults with COPD, and the multi-factorial benefit of pulmonary rehabilitation.

This research will be important to health professionals working with COPD patients, as they require increased awareness regarding the factors influencing health behaviour change, including barriers and enablers, to better target interventions in COPD management and to improve effectiveness of self-management education. An emphasis should be placed on
early intervention which includes referral to pulmonary rehabilitation and enhanced education regarding self-management strategies. Indeed, many of the participants in the current study went for years understanding very little about their disease or how to manage it.

In pulmonary rehabilitation health professionals should not only understand health behaviour models and theories in designing our interventions aimed at health behaviour change, but also take into consideration other influences on health behaviour, as described in the current study. When assessing patients, health professionals should ensure to address the external and personal factors influencing health behaviour such as other health co-morbidities, social support, other life demands, self-determination, and confidence and control to ensure interventions that support health behaviour change are planned. Anxiety and depression are common in this population and can interfere with health behaviour change. Pulmonary rehabilitation programs should include the appropriate support and/or interventions to address anxiety and depression.

Of particular importance, health professionals should address patients’ social support systems in pulmonary rehabilitation. Education on COPD management and health behaviour strategies should be shared with families, especially with spouses. Whether this involves inviting spouses to attend program components, or encouraging patients to share the information with their loved ones, it is very important to capitalize on this resource to encourage and sustain health behaviour change in our patients. Participation in maintenance programs and/or peer support groups should be encouraged particularly for at-risk individuals (those who live alone, have symptoms of anxiety or depression, have multiple co-morbidities, and higher MRC score).
This study has important implications for occupational therapy practice. The models presented here describe the process of health behaviour change as one that has an individual at its core, with behaviour being influenced by personal factors such as confidence, motivation, and outlook, and external factors such as the environment and social support. This interaction between the individual and their environment resonates well with the profession of occupational therapy. Occupational therapy as a profession is very much concerned with the dynamic relationships between individuals, their environments, and their occupations (everyday activities and life roles) as illustrated by theoretical frameworks underpinning the profession, such as the Canadian Model of Occupational Performance, and the Person-Environment-Occupation Model (Canadian Association of Occupational Therapists, 1997). According to a survey of pulmonary rehabilitation programs across Canada, occupational therapists are relatively underrepresented as health professionals in pulmonary rehabilitation programs, citing respirologist, physiotherapists, respiratory therapists, and pharmacists as the most frequently represented health professionals (Brooks, et. al, 2007). Occupational therapists have a great deal to offer in understanding and promoting health behaviour change in individuals and populations, and the role of occupational therapy in pulmonary rehabilitation should be promoted.

**Directions for future research**

Further research can build on the results of the current study. For example, further qualitative research could explore the relationships among the constructs represented in the model to better understand the processes behind them (e.g. how social support influences health behaviour or how pulmonary rehabilitation increases confidence). This would inform clinicians regarding how to best incorporate social supports into health behaviour change.
interventions and what components of pulmonary rehabilitation should be emphasized to increase confidence. In addition, further research should be conducted applying the model to a larger sample to test the relationships among constructs, and to validate the model with other populations.

Empirical testing of the model with a larger sample could also lend to the development and validation of an assessment tool to identify potential barriers and/or enablers to health behaviour change. This would be beneficial to clinicians to allow them to target interventions taking into consideration the factors influencing individuals’ health behaviour (i.e. external and personal factors).

This study identified that some older adults with COPD had started to engage in health behaviour strategies prior to pulmonary rehabilitation. Further research along the lines of adaptation to chronic illness might bring to light some important findings that could improve how we deliver self-management and health behaviour education to individuals with COPD.

Finally, this study lends support to the following research needs identified in existing literature: 1) to determine the mechanisms or components of pulmonary rehabilitation, follow-up, and maintenance programs that prolong the benefits achieved in pulmonary rehabilitation (i.e. the length or duration of programs, the frequency of contact with a health professional, etc.) (ATS, 2006; Derom et al., 2007); and 2) to determine to best way to address anxiety and depression in pulmonary rehabilitation (e.g. psychotherapy, cognitive behavioural therapy) (Derom et al., 2007).
References


Study Title: Exploring the Health Behaviours of Older Adults with Chronic Obstructive Pulmonary Disease (COPD)

Purpose: This study is being done to improve our understanding of how older adults with COPD incorporate what they’ve learned about coping with and managing their disease into their daily lives, following respiratory rehabilitation. In particular, we are interested in learning about some of the things that help or interfere with being able to take care of one’s own health.

You are being invited to participate in this study because you have attended the Respiratory Rehabilitation Program at West Park Healthcare Centre, and you are 55 years of age, or older. Please keep this information sheet for your own reference.

While this project is being conducted as a requirement for a Master’s thesis, for the principal investigator, the results of this study will also be shared with the Respiratory Rehabilitation Program in an effort to improve care delivery for future patients.

Description: Your participation in this study will involve an hour of your time. The researcher will meet with you in your own home to conduct an interview (or at West Park, if you prefer). You will be asked about your experience of living with COPD and how you manage your health. There are no right or wrong answers; we are interested in hearing about your experiences. Ten to fifteen participants will be interviewed as part of this study. If you give permission following your interview, you may be contacted at a later time to provide feedback on the study results.

Benefits: There are no direct benefits to you for participating in this study. However, the results of this study may benefit others with COPD by helping health professionals to assist patients in learning how to manage their COPD in the best way possible.
**Potential harms:** There may be some uncomfortable feelings brought about in describing any difficulties or frustrations experienced in living with COPD during the interview. The researcher will provide information on support services, as needed.

**Confidentiality:** Your participation in this study will be kept strictly confidential, and no information regarding your identity will be released or published. All information collected from you will be assigned a code to maintain anonymity, and will be kept under lock and key by the researcher for up to 6 years, after which time it will be destroyed. In publication of the study results, quotes may be published, but anonymity will be maintained.

**Participation:** You may choose to refuse to participate in this study or withdraw at any time during its course. Your decision to refuse or withdraw will in no way influence your relationship with West Park Healthcare Centre and will have no influence on your medical or therapy management. Once the study has been completed, you are welcome to request a copy of the results.

If you are interested in participating in this study, please contact the researcher listed below for more information. You may expect a follow-up telephone call in approximately 2 weeks from a staff member from the Respiratory Program to answer any questions you may have regarding this study.

Thank you very much for your interest,

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Shirley Price, BSc(OT), MSc(candidate)
Principal Investigator
Graduate Department of Rehabilitation Science,
University of Toronto, and
Clinical Practice Leader, Occupational Therapy
Respiratory Services,
West Park Healthcare Centre
416-243-3600 x2290
Study Title: Exploring the Health Behaviours of Older Adults with Chronic Obstructive Pulmonary Disease (COPD)

I have read the participant information sheet. The research study and procedures have been explained to me and my questions have been answered to my satisfaction. I know I may ask any other questions I have at any time during the study. Any foreseeable harms have been explained to me, and I understand there will be no direct benefits to me to participate in this study. I will receive a copy of both the information sheet and this consent form for my own reference.

I understand that my interview will be recorded on tape and I may decline to answer any questions I choose. I am aware that any information I supply will be kept strictly confidential, and will be destroyed 6 years after completion of the study. I understand my identity will be not be released or made public at any time, and that my anonymity will be maintained in any publication of the study results.

I am aware that participating in this study is voluntary. If I choose not to participate and/or I withdraw from this study at any time, I understand that this decision will not affect my relationship with West Park Healthcare Centre, nor will it have any influence on my medical or therapy management now, or in the future.

I know that if I have any concerns in the future about my rights as a research participant, I can call Tim Pauley, Research Coordinator at West Park Healthcare Centre at 416-243-3600 x2628.

________________________   __________________________   _____________
Participant    Signature       Date

________________________   __________________________   _____________
Investigator    Signature       Date
**APPENDIX C**  
Measure of Severity of Lung Disease

 Forced Expiratory Volume in 1 second; Forced Vital Capacity (FEV₁; FVC)

<table>
<thead>
<tr>
<th>FEV₁; FVC</th>
<th>Severity of lung disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 80% of predicted; FVC &lt; 0.7</td>
<td>mild</td>
</tr>
<tr>
<td>≥ 50% &lt; 80% of predicted; FVC &lt; 0.7</td>
<td>moderate</td>
</tr>
<tr>
<td>≥ 30% &lt; 50% of predicted; FVC &lt; 0.7</td>
<td>severe</td>
</tr>
<tr>
<td>&lt; 30% of predicted; FVC &lt; 0.7</td>
<td>very severe</td>
</tr>
</tbody>
</table>

APPENDIX D          MRC Dyspnea Scale

<table>
<thead>
<tr>
<th>Grade</th>
<th>Level of Breathlessness with Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Breathless with strenuous exercise</td>
</tr>
<tr>
<td>2</td>
<td>SOB when hurrying on the level or walking up a slight hill</td>
</tr>
<tr>
<td>3</td>
<td>Walks slower than people of the same age on the level or stops for breath while walking at own pace on the level</td>
</tr>
<tr>
<td>4</td>
<td>Stops for breath after walking 100 yards</td>
</tr>
<tr>
<td>5</td>
<td>Too breathless to leave the house or breathless when dressing</td>
</tr>
</tbody>
</table>

# APPENDIX E  Sociodemographic Characteristics of Sample

<table>
<thead>
<tr>
<th>Sociodemographic Characteristics</th>
<th>Summary of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 11</td>
</tr>
</tbody>
</table>

| Gender (Male/Female)             | M = 6; F = 5              |
| Age                              | Range=59-78; Average = 70; Median = 68 |
| Other Health Conditions/Issues   | 0-2 other co-morbidities = 5  
                                  | 3-6 other co-morbidities = 6  
                                  | (e.g. osteoarthritis, hypertension, heart disease, osteoporosis, crohn’s disease, asthma, diabetes) |
| Oxygen User                      | Y = 3; N = 8              |
| Smoking History                  | Y = 11                    |
| Marital Status                   | Married = 6  
                                  | Widowed = 2  
                                  | Separated = 3 |
| Social Support (living with spouse/family, alone) | Living with spouse = 6  
                                  | Living with other family = 1 (adult child)  
                                  | Living alone = 4 |
| Living Environment (house – 1 or more stories, apartment, stairs) | 2 storey house = 3  
                                  | bungalow = 4  
                                  | condo/apartment = 4 |
| Educational Background           | Less than secondary = 3  
                                  | Some secondary = 4  
                                  | Some post-secondary/completed post-secondary = 4 |
| Employment Status/History        | Retired due to health = 6  
                                  | Retired due to age = 4  
                                  | Never worked outside = 1 |
| Ethnic Background                | Canadian (1\textsuperscript{st} or 2\textsuperscript{nd} generation) of following descent: English, Irish, Welsh, Dutch, Swiss, French, Russian |
| Time Since Completed Rehab       | < 6 months = 4  
                                  | 6 months < 1 year = 2  
                                  | 1 < 2 years = 2  
                                  | = 2 years = 3 |
| Participation in Maintenance Program | Y = 5; N = 6 |
| MRC Dyspnea Scale                | MRC of 2 = 3  
                                  | MRC of 3 = 3  
                                  | MRC of 4 = 5 |
| Severity of disease              | moderate = 3  
                                  | severe = 8 |
Q.1. Tell me how living with COPD has affected your daily life?
    Possible probes:
    • Effect of symptoms on daily activities
    • Effect on coping abilities
    • Mood/anxiety

Q.2. What do you do to manage your COPD, on a daily basis?
    Possible probes:
    • What are the important things you need to do to maintain your health/how do you incorporate those things into daily activities?
    • Are there things you would like to do, that you are not, to maintain your health?
    • What were you doing before pulmonary rehabilitation?
    • What are you doing differently following pulmonary rehabilitation?

Q.3. What helps you to be able to manage your COPD?
    Possible probes:
    • Supports available/Environment
    • Encouragement

Q.4. What makes it difficult to manage your COPD?
    Possible probes:
    • Barriers to taking care of yourself
    • Effect of environment/things you have no control over