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‘There is More to Supervised Exercise than Exercise Itself’

A Mixed Methods Study of Supervised Exercise with the Chronic Disease Self-Management Program for People with COPD

By

HELEN L. CAMERON-TUCKER, BPhy (Hons)

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Menzie's Research Institute and Faculty of Education, University of Tasmania

(Hobart)

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DECLARATION OF ORIGINALITY

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ABSTRACT

‘THERE IS MORE TO SUPERVISED EXERCISE THAN EXERCISE ITSELF’

A Mixed Methods Study of Supervised Exercise with the Chronic Disease Self-Management Program for People with COPD

Chronic obstructive pulmonary disease (COPD), a progressive respiratory condition, significantly affects the lives of those managing its daily impact. Exercise is recognised as an important management strategy. This thesis investigates the addition of supervised exercise to the Stanford Chronic Disease Self-Management Program (CDSMP) in people with COPD. The CDSMP is a group-based program designed to facilitate the acquisition of self-management skills, and does not have an exercise component.

This thesis provides opportunity to consider theories of health behaviour change and the role of self-efficacy in the self-regulation of behaviours, such as exercise. The effect of the CDSMP on self-reported exercise was reviewed, finding a lack of published research concerning supervised exercise with the CDSMP.

To investigate the effect of supervised exercise with the CDSMP older adults were allocated to the CDSMP, with or without supervised exercise, in a parallel group randomised controlled clinical trial with a pre/post test design over two years. A mixed methods approach was used to provide a more detailed analysis of the effect of supervised exercise than one method alone, giving quantitative evidence enriched by the lived experience of participants. Objective outcomes included physical capacity (primary outcome), self-reported exercise, stage of change for exercise, exercise self-efficacy, shortness of breath, health-related quality of life and self-management behaviours. Change in outcomes between groups and within group was measured by appropriate statistical tests. Qualitative methods of enquiry using semi-structured interviews and thematic analysis uncovered the lived experience of the people who participated in the CDSMP with or without supervised exercise.

Eighty-four participants were randomised. There were 15 withdrawals, due to ill-health and other commitments. This thesis demonstrated a small statistically

significant increase in physical capacity for the intervention and control groups, but no significant difference between them. However, the clinical significance of the within-group change was not reached. Further research is required in this area. There were no significant differences between groups for any secondary outcome, although analysis of effect sizes indicated that supervised exercise confers a benefit to those who participate: they exercised more frequently, for longer duration, had less breathlessness and improved quality of life physical component summary compared with those who did not have supervised exercise. However, neither one hour of weekly supervised exercise, in the absence of a structured home programme, nor the CDSMP alone, was sufficient to produce more than small improvements in outcomes.

Qualitative findings revealed participants bring to healthcare interactions a personal meaning of self-management defined by their lived experiences and strategies developed in response to living with COPD. Similar sources of motivation act across the CDSMP and supervised exercise, thereby supporting the construct of self-efficacy and signifying the pivotal role of perceived personal control as a mediator of behaviour change. However, the experience was not viewed positively by all, indicating the need to be alert to possible adverse psychological effects of interventions and to identify at-risk individuals. Participants endorsed supervised exercise, emphasising the importance of respecting their preferences.

This study suggests that the process of facilitating behaviour is not concerned with ‘who knows best’, but rather with how the interaction between health professional and participant facilitates a consideration of self and the best possible behaviours to manage life with long-term health conditions, pointing to a framework for participant-centred engagement in healthcare.

In conclusion, supervised exercise of one hour per week does not need to be an integral component of the CDSMP, but offered as an optional adjunct, underpinned by a participant-centred approach. Methods of increasing the clinical significance of the small increase in distance walked need to be explored.

DEDICATION

This thesis is dedicated to the participants who willingly gave of their time and themselves during the research, regardless of the severity of their condition. ‘Barry’ and ‘Gary’, two participants who agreed to be interviewed have sadly died. They will be remembered through the insights they openly shared with me.

I also dedicate this thesis to my husband, Rodney, and four daughters, Belinda, Angela, Victoria and Olivia who have encouraged and supported me and each other through very exciting and also some challenging times.

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1

CHAPTER ONE

CONTEXT TO THE THESIS

1.1 Introduction

This chapter provides the context to the thesis. The timeliness of this research is explained with reference to an increasing prevalence of COPD, an increasing acknowledgement of the health-related benefits of exercise for people with COPD and an increasing focus on self-management of chronic diseases with introduction of programmes such as the Chronic Disease Self-Management Program (CDSMP). Theories explaining how adoption of health-related behaviours may be facilitated are explored, with particular reference to the construct of self-efficacy and its role in the regulation of human behaviour. By understanding how behaviour may be influenced, health professionals will be better situated to assist those for whom behaviour change may be necessary.

As it will become clear in *Chapter Two, Literature Review*, there is an increasing recognition that an acute model of medical care is not optimal for helping people manage the demands of living with long-term health conditions, or for incorporating behaviour changes that day-to-day disease management may require. Thus alternative approaches are being sought. A framework that recognises the person as an active partner in their healthcare is being increasingly referred to in the literature (Booth et al. 2000; Gerteis 1993; Harkness 2005; Laine & Davidoff 1996; Lewin et al. 2001; Little et al. 2001; Lorig 2002; Mead & Bower 2002; Shoor & Lorig 2002; Stewart 2001; Toop 1998; Von Korff et al. 1997; Wagner, Austin & Von Korff 1996). Such a structure is endorsed by the International Alliance of Patients' Organizations (International Alliance of Patients' Organizations 2006) and this collaborative approach will be explored further in this thesis.

1.2 Prevalence of COPD

The need to consider the management of COPD is seen in a context of increasing prevalence, incidence and burden of chronic diseases, described as reaching epidemic proportions in Australia (Australian Institute of Health and Welfare 2001) and worldwide (World Health Organization 2003b). COPD is a chronic progressive, disabling condition characterised by airflow limitation or obstruction due to an abnormal inflammatory response of the lungs to inhaled noxious substances, especially cigarette smoke (Global Initiative for Chronic Obstructive Lung Disease [GOLD] 2007). Australia's prevalence of COPD in 2004–5 was estimated at 3% (Australian Institute of Health and Welfare 2006) compared to the estimated worldwide prevalence of 4–10% (Halbert et al. 2003). However, the true prevalence of COPD is difficult to estimate and is probably underestimated, because definitions vary and surveys rely on self-report of chronic bronchitis and/or emphysema (Australian Institute of Health and Welfare 2005). The inflammatory response of the lungs does not usually become symptomatic until years after its onset, in the fifth to seventh decades of life, resulting in delayed diagnosis (Bellamy, Booker & Fardy 2003).

In Australia the smoking rate for men has decreased over the past thirty years, suggesting there may be a decrease in COPD prevalence in this group as we move into the 21st century. However, with a greater proportion of females smoking since the late 1970s, it is expected that overall prevalence of COPD will continue to rise (Mannino 2003) and contribute to an increasing health burden in Australia (Australian Institute of Health and Welfare 2005; Bellamy, Booker & Fardy 2003).

At an individual level, COPD exacts a substantial burden in terms of breathlessness, limitations to physical and social activities and impaired quality of life (MacNee & Rennard 2004). Interventions ultimately aim to help people achieve the best possible health while managing the day-to-day demands of life with a long-term health condition. As a prelude to describing such interventions, health is defined in the following section, and its determinants considered.

1.3 Health

1.3.1 Definition of Health

Health may be defined from a bio-psychosocial viewpoint wherein it is seen as being well physically, mentally and socially (Tulloch 1995; World Health Organization 1946) and not simply the absence of disease (World Health Organization 1946). Others have considered this definition too broad and have defined health as a combination of function and prognosis, enabling the concept to be measured mathematically (Patrick, Bush & Chen 1973). In addition there is a personal dimension, moulded by personal circumstances, experience, perceptions, values and expectations (Eweles & Simnett 2003; McMurray 2002). Spiritual and emotional dimensions also contribute to a personal meaning of health (Eweles & Simnett 2003). Self-perception appears to be integral to a state of health, in that how people perceive themselves has an impact on their psychological wellbeing, which in turn can influence physical and social wellbeing (Kempen et al. 2005). This is especially so when life with a chronic condition threatens a sense of self (Charmaz 1983, 1987) .

Health is also seen in a broader context, enabling people to lead a balanced life (McMurray 2002) and to be productive participants in their work and community (World Health Organization 1981). The importance of health is outlined in the Ottawa Charter for Health Promotion (World Health Organization 1986) as a state of wellbeing, achieved when an individual or a group is able to respond to the environment while identifying and meeting their needs and ambitions, pointing to health as a 'resource' needed for daily life and not the purpose of living. Good health is needed for economic, social and personal growth (World Health Organization 1986).

In summary, health is a dynamic entity, reflecting a state of wellbeing — the best possible self-perception, physical, mental, social, emotional and spiritual state that is drawn upon in response to the environment in which the individual finds themselves. The factors that influence or determine health and that may consequently be targeted as areas of potential intervention are discussed in the following section.

1.3.2 Determinants of Health

The determinants of health may act singly or, more commonly, interact to influence a person's overall wellbeing (Australian Institute of Health and Welfare 2002, 2006; McMurray 2002). As these authors explain, health may be influenced by:

- biological factors relating to a person's genetic make-up
- individual factors including age, gender, lifestyle choices, behaviours, attitudes and beliefs
- environmental factors pertaining to physical, chemical, biological, socioeconomic, cultural, religious and political influences
- health service delivery including accessibility, quality and response to a person's needs
- policy from governments and institutions to implement and deliver health services.

One way by which intervention programmes may influence the health of people with COPD is to target healthy lifestyle behaviours such as exercise adoption. Some authors assert that a person's attitudes and beliefs affect the decisions they make concerning their lifestyle behaviours, in turn affecting biomedical markers and ultimately health (Australian Institute of Health and Welfare 2002). However, some psychologists state that the evidence points to behaviour influencing attitudes (Augoustinos & Walker 1995). Whatever the pathway, the literature suggests an attitude-behaviour or behaviour-attitude link with respect to health-related lifestyle choices such as smoking, undertaking exercise or having a healthy diet. The effect of interventions such as cardiopulmonary rehabilitation (Lacasse et al. 2006) or the CDSMP (Lorig, Sobel et al. 1999) on health behaviours such as exercise has been the subject of prior research. However, there appears to be a lack of research into their effects on attitudes, indicating a need for research in this area.

This research sought to investigate the effect of adding supervised exercise to the CDSMP. As a first step, exercise is defined, health benefits of exercise for people with COPD described, and theories explaining the adoption of health behaviours are briefly introduced in the following section.

1.4 Exercise

Exercise is considered a key component of interventions offered to people with COPD and is advocated in recently published guidelines (Nici et al. 2007; Abramson 2006; Ries et al. 2007), systematic reviews (Lacasse 2006) and studies of pulmonary rehabilitation (Cockram, Cecins & Jenkins 2006; Elliott et al. 2004; Finnerty et al. 2001; Griffiths et al. 2000; Hui & Hewitt 2003; Miyahara et al. 2000; Singh et al. 2003; Troosters, Gosselink & Decramer 2000). (See Table 33 for details.) This section outlines the benefits of exercise for individuals with COPD, and how its adoption might be facilitated.

1.4.1 Definition

It is relevant for this thesis to define the terms ‘physical activity’ and ‘exercise’, which are often used interchangeably. Physical activity refers to any movement of the body (Tulloch 1995), including structured exercise (Seiler 2000; Speck 2002). ‘Exercise’ is defined as purposeful activity done for training or to maintain or improve health (Tulloch 1995). Exercise is therefore a subset of physical activity. A focus of this thesis is the effect of supervised exercise done to improve or maintain health. Therefore, the term ‘exercise’ will be used in a context of exercise for health rather than exercise for training or fitness, except in situations where ‘physical activity’ is in common use, such as in government or health guidelines, population health messages or questionnaire names.

1.4.2 Health Benefits of Exercise

The seminal report in 1996 of the Surgeon General of the United States illuminated the importance of exercise in bestowing health benefits for all (United States Department of Health and Human Services 1996). Since then the health benefits of regular exercise have been summarised by a number of authors and are listed below (Bauman & Smith 2000; Egger et al. 1999; Giorgianni, Grana & Sewell 2002; Sewell & Morgan 2002; Sherwood & Jeffery 2000; World Health Organization 2003a):

- decreased risk of premature death from all causes
- decreased risk of developing chronic conditions (cardiovascular disease, type 2 diabetes and colon cancer) and protection against risk factors

- decreased decline in pulmonary function
- improved psychological function and cognition
- decreased decline in musculoskeletal strength, flexibility and coordination which in turn results in decreased risk of incidence of falls and fractures, especially in the elderly.

These benefits are also conferred on those with COPD, and are expanded upon below.

1.4.2.1 Decreased All-cause Mortality

Increased levels of exercise and physical fitness are associated with decreased mortality. Studies have varied with respect to the independent variable under scrutiny (Egger et al. 1999). Exercise has been measured with respect to frequency and intensity (Kujala et al. 1998) or frequency, intensity and duration (Finucaine et al. 1997), as opposed to physical fitness that has been measured by a bicycle (Erikssen et al. 1998) or treadmill test (Blair et al. 1995). However measured, the association of regular exercise or physical fitness with beneficial health outcomes has been demonstrated across a range of studies, as presented below.

Early epidemiological studies found lower levels of physical activity in London bus drivers were inversely associated with fatal coronary disease (Morris et al. 1953). More recently a 22-year longitudinal cohort study in Norway of 2,014 healthy men aged 40 to 60 years also found an inverse relationship between physical fitness, as measured by a bicycle exercise tolerance test, with cardiovascular mortality and all-cause mortality. The relative risk of death from any cause was 0.45 (95% confidence interval 0.29–0.69) for the fittest compared with 1.00 for the least fit (Erikssen et al. 1998). Similar findings were seen in an earlier prospective five-year follow-up study of 9,777 healthy men that demonstrated a 7.9% decrease in risk of mortality with each additional minute walked during a treadmill exercise tolerance test (Blair et al. 1995).

Studies involving older adults with chronic conditions have particular relevance for people with COPD, many of whom are older. In a cohort of frail elderly Italian adults (78.2 ± 9.5 years of age, $n = 2,757$) admitted to home health agencies, chronic conditions included cardiovascular disease, diabetes, cancer, renal failure,

depression, cognitive impairment and COPD. Those who engaged in moderate intensity exercise or physical activity (light housework, gardening, specific exercises or walking) for greater than two hours per week had decreased all-cause mortality across age groups. The relative risk ratio of dying for most active participants compared with least active was 0.51 (95 % confidence interval 0.35–0.73) (Landi et al. 2004).

A random sample of community dwelling people aged 40 and over with two or more of the chronic conditions of heart disease, diabetes, dyslipidemia or hypertension completed a mail survey of physical activity levels (Martinson, O'Connor & Pronk 2001). Low levels of exercise (less than 30 minutes per week) were associated with increased mortality recorded in the ensuing 3½ years. Compared with people attaining more than 30 minutes of exercise in the previous week, the risk ratio of mortality for the least active group was 2.15 ($p < 0.001$) after adjusting for confounding variables. The authors also observed the least active people in this study were most likely to benefit from increasing physical activity levels.

Unfortunately, as Ries et al. (2007) point out, most studies concerning mortality following pulmonary rehabilitation that include exercise are observational. One randomised controlled study of pulmonary rehabilitation reported increased survival at six years for participants compared with controls who received education only (67% versus 56%). Although, the results did not reach statistical significance ($p = 0.3$), this indicates that moderate exercise is associated with reducing all-cause mortality and clearly more research is needed in this area (Ries et al. 2007).

1.4.2.2 Decreased Risk of Developing Chronic Conditions and Modification of Risk Factors

Following an extensive review of the literature, the National Institute of Health Consensus Panel concluded that 30 minutes of moderate physical activity conferred protective health benefits with respect to developing cardiovascular disease (National Institute of Health 1996). This conclusion is supported by an earlier meta-analysis of studies showing there was a relative risk of death from heart disease of 1.9 (95% confidence interval: 1.6–2.2) for people in sedentary versus active occupations (Berlin & Colditz 1990). The authors concluded that exercise or being physically

active was positively associated with the prevention of coronary heart disease and, as such, is a major modifiable risk factor.

Higher levels of exercise are also associated with reduced risk of type two diabetes, as evidenced by two recently reported randomised controlled trials of at-risk mature-age people (The Diabetes Prevention Group 2002; Tuomilehto et al. 2001). Both studies found a reduced incidence of diabetes following an intervention that targeted diet and exercise when compared with usual care (Tuomilehto et al. 2001) or metformin (The Diabetes Prevention Group 2002). In comparison to usual care, participants who exercised for 240 minutes per week and reached a target weight had a decreased incidence of diabetes of 58% (Tuomilehto et al. 2001). In comparison to metformin, people who exercised for 150 minutes per week and reached a target weight also had a decreased incidence of diabetes of 58% (The Diabetes Prevention Group 2002). Unfortunately, the relative contribution of exercise cannot be deduced from these studies as the researchers did not seek to investigate the differential effects of dietary change, weight loss or exercise.

1.4.2.3 Decreased Decline in Pulmonary Function

Lung function declines with age after full maturity is achieved, thus age is a factor contributing to the decline in lung function seen in COPD (Bellamy, Booker & Fardy 2003). Some authors have found no modifying effect of exercise on decline in lung function. In a longitudinal study comprising a small cohort of 18 fit and healthy older adults, physiological parameters of lung function declined in keeping with healthy ageing, despite the participants' high level of fitness (McLaran et al. 1995). However, other studies have shown a positive association.

In a cross sectional study of 3,111 elderly Japanese-American men, physical activity levels were positively associated with forced vital capacity (FVC) and forced expiratory volume in one second ($r = 0.14$, $p < 0.001$) (Burchfiel et al. 1997). More recently, a 25-year longitudinal follow-up study of Finnish men concluded that the more physically active a person was, the less their lung function declined, irrespective of their smoking status. The researchers reported that for men in the highest tertile of physical activity, lung function — as measured by forced expiratory volume in 0.75 seconds — declined by 36.5 (confidence interval -42.9, -30.1) millilitres per year as opposed to 44.4 (confidence interval -46.8, -40.1) millilitres

per year for men in the lowest tertile over the 25-year period ($p = 0.043$) (Pelkonen et al. 2003). As smoking contributes to the development of COPD (MacNee & Rennard 2004; Pelkonen et al. 2003), this observation suggests that exercise should be encouraged for people with this condition.

1.4.2.4 Improved Psychological Function and Cognition

There is also evidence that exercise improves cognitive function and psychological wellbeing for people with COPD (Emery et al. 2001; Emery et al. 1998). Others have also reported improved psychological function following cardiopulmonary rehabilitation, but have not isolated the effect of exercise (Griffiths et al. 2000; Lacasse et al. 2006; Ries et al. 1995). Emery and colleagues (1998) investigated the effect of 10 weeks of exercise with an education and stress-management programme. The 29 participants randomly assigned to exercise, education and stress-management reported decreased anxiety ($p < 0.01$) and improved verbal fluency, a marker of cognitive functioning ($p < 0.001$) when compared with 25 participants receiving education and stress management but no exercise and with 25 waiting list controls. In a study investigating the acute effects of exercise, verbal fluency was seen to improve after just 20 minutes of exercise when compared with a video control in 29 participants randomly assigned to each intervention a week apart ($p < 0.01$) (Emery et al. 2001).

1.4.2.5 Decreased Decline in Musculoskeletal Strength

Decreased exercise compounds the declines in the musculoskeletal systems associated with age: decreased muscle power, strength and endurance, decreased joint flexibility, decreased bone strength and decreased functional ability including balance and coordination (Vuori 1995). As a result of this impairment, individuals are at a greater risk of falling. A meta-analysis concluded that both general and specific balance exercises reduce the risk of falling in adults aged 60–75 years (Province et al. 1995). A recent study of 59 men (mean age 74 years) showed that a 12-week exercise programme reduced the risk of falls (6 falls per 1000 hours of activity for the intervention group versus 16.2 falls per 1000 hours of activity for controls, $p < 0.05$) when adjusted for exercise level (Rubenstein et al. 2000).

The importance of the positive effect of exercise on the musculoskeletal body systems has significance for people with COPD. It is now recognised that people with COPD experience skeletal muscle dysfunction (American Thoracic Society and European Respiratory Society 1999; Nici et al. 2007). This is particularly so for the muscles of ambulation, which exhibit decreased strength (Mador & Bozkanat 2001; Nici et al. 2007). The American Thoracic Society and European Respiratory Society position statement details this phenomenon (American Thoracic Society and European Respiratory Society 1999). In brief, it is suggested that the dysfunction is due to deconditioning as a result of decreased exercise and an increasing sedentary lifestyle, malnutrition resulting in profound muscle wasting, reduced circulating anabolic hormones that influence muscle growth, decreased oxidative enzyme capacity that impairs muscle metabolic capacity, the effect of oral corticosteroids that induce myopathies and perhaps to a COPD-specific myopathy (Casaburi 2003; Rochester 2003). Exercise is now regarded as the best means of improving the skeletal muscle dysfunction associated with COPD and a major factor in improving exercise intolerance in this group of people (Mador & Bozkanat 2001; Nici et al. 2007; Rochester 2003).

Exercise is seen as a major modifiable health-related behaviour (Joint Advisory Group on General Practice and Population Health 2001). However, despite the clear benefits, less than 50% of adult Australians achieve the minimum recommended daily levels of exercise (Armstrong, Bauman & Davies 2000; Australian Institute of Health and Welfare 2003). Indeed, physical inactivity is estimated to account for 7% of the burden of disease in Australia (Mathers et al. 2000). Various theories have attempted to explain the adoption of health-related behaviours such as exercise, the intervention evaluated in this thesis. Those most frequently referred to are briefly outlined below.

1.4.3 Behavioural Change: Adoption of Exercise

Adopting or maintaining health behaviours such as exercise is a complex task. The person must first be motivated to do so, be confident and capable of fulfilling the intention and translating the intention into action. The lag between intending to make a health-related behaviour change, such as adopting exercise, and making the change has been referred to as the 'intention-behaviour gap' (Sniehotta, Scholz & Schwarzer

2005). Crossing this gap is important: if it is not crossed, then the implied health benefits of exercise will not be realised.

Various models and theories have attempted to explain how people adopt health behaviours such as exercise and how their behaviour might be influenced. The most commonly cited models are the health belief model (Becker 1974), the transtheoretical model of change (Prochaska 1984), the theory of reasoned action (Ajzen & Fishbein 1980) and social cognitive theory (Bandura 1986). It is beyond the scope of this thesis to discuss all of these models in detail, which have been synthesised by others (Glanz, Lewis & Rimer 1997; Redding et al. 2000). However, a brief discussion follows.

The health belief model postulates that people take action to manage their health if they believe they are susceptible to developing a condition or if they believe their actions might decrease the perceived severity of the condition. The benefits of action outweigh the barriers (Becker 1974). The theory of reasoned action suggests that behaviour is under volitional and rational control and is modified by attitudes. It considers that the behaviour will elicit the desired outcome and is modified by social influence in the form of beliefs that are considered to be the 'social norm' (Ajzen & Fishbein 1980). The transtheoretical model of change proposes that people incrementally adopt behaviours, moving through five stages of change (pre-contemplation, contemplation, preparation, action and maintenance) usually in a cyclical manner, using various processes or strategies during this endeavour (Prochaska 1984). Social cognitive theory espouses a reciprocal interaction between environmental, individual and behavioural factors as the individual engages in a cycle of self-regulating behaviour (Bandura 1986).

With the exception of the theory of reasoned action, self-efficacy — a belief in one's ability to achieve a desired outcome under varying circumstances (Bandura 1986) — is a construct common to the above models and to many other approaches to health behaviour change (Clark & Dodge 1999; Clark, Gong & Kaciroti 2001; Schwarzer 2001; Schwarzer & Renner 2000; Strecher et al. 1986). Self-efficacy for managing one's condition is commonly measured as an outcome of the CDSMP by a participant-completed questionnaire devised by Stanford University (Lorig et al. 1996). The chronic disease self-management (CDSM) literature consistently reports

statistically significant increases in self-efficacy for self-management in the United States (Lorig, Ritter & Gonzalez 2003; Lorig, Sobel et al. 1999); in China (Fu et al. 2003; Siu et al. 2007), in the United Kingdom (Wright et al. 2003), and in Australia (Swerissen et al. 2006). However, a recent Dutch study found no statistically significant change in self-efficacy following the CDSMP (Elzen et al. 2007), the only published study to date showing no effect. The authors suggested that the negative result may be due to the high baseline self-efficacy of the participants, or to publication bias wherein studies reporting negative results were not published. There is no reference to exercise self-efficacy as an outcome of the CDSMP.

Although discussions concerning the construct of self-efficacy for breathlessness or exercise have featured in the COPD-related literature for more than a decade (Atkins et al. 1984; Kaplan et al. 1994; Scherer & Schmieder 1996; Toshima, Kaplan & Ries 1990; Zimmerman, Brown & Bowman 1996), it is only recently that self-efficacy is appearing in relation to intervention programmes (Bourbeau, Nault & Dang-Tan 2004; Monninkhof et al. 2003). The focus on self-efficacy development in the CDSMP is a differentiating feature from traditional cardiopulmonary rehabilitation programmes, which will be discussed in *Chapter Two*.

The meaning of self-efficacy and its acknowledged role in behaviour regulation, with reference to the CDSMP and for people with COPD, will be discussed later in this chapter. Firstly, the CDSMP and self-management will be described in detail in the following sections.

1.5 The Chronic Disease Self-Management Program

Traditionally in Australia, comprehensive cardiopulmonary rehabilitation programmes, with exercise as a key component, are the recommended approach for people with COPD (Abramson et al. 2006; American Thoracic Society 1999; Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2007; McKenzie, Frith & Burdon 2003; Nici et al. 2007; Ries et al. 2007). With Australian (National Health Priority Action Council 2006) and Tasmanian governments (Department of Health and Human Services 2005) focusing on management of chronic conditions, health professionals involved in coordinating the cardiopulmonary rehabilitation programme at a tertiary teaching metropolitan hospital in Tasmania, a southern

Australian state, undertook training in the Stanford CDSMP (Lorig, Gonzalez & Laurent 1999) . This approach is designed to help people with chronic conditions such as COPD ‘self-manage’ the day-to-day impact of the condition on their lives. Subsequently, the CDSMP was offered at the hospital instead of the more traditional cardiopulmonary rehabilitation programme.

Born of the *Arthritis Self-Management Program* (Lorig et al. 1985) and grounded in behaviour change theoretical concepts, the CDSMP is a 6-week programme with sessions of 2½ hours duration offered weekly (Lorig, Gonzalez & Laurent 1999) . The CDSMP is built upon patient-perceived issues, acknowledging and including participants as partners during the programme. It recommends working in collaboration with healthcare professionals in the self-management of the chronic condition. This situates the CDSMP in a participant-centred approach, which will be discussed further in following chapters.

The CDSMP is a highly structured group-based programme facilitated by pairs of trained leaders who have undertaken 24 hours of training. It offers generic education about health-related behaviours and aims to facilitate the development of self-management self-efficacy through guided feedback sessions, problem-solving and completing action plans to achieve participant-defined goals (Lorig, Gonzalez & Laurent 1999) It does not include supervised exercise.

The CDSMP is being implemented worldwide. Studies of the effect of the CDSMP on health outcomes have been published from research occurring in:

- Australia (Bell & Orpin 2006; Swerissen et al., 2006)
- the United States (Farrell, Wicks & Martin 2004; Lorig, Ritter et al. 2001; Lorig, Ritter & Gonzalez 2003; Lorig, Ritter & Plant 2005; Lorig, Sobel et al. 1999)
- the United Kingdom (Bancroft, Barlow & Turner 2004; Barlow, Bancroft & Turner 2005a, 2005b; Barlow et al. 2005; Griffiths et al. 2005; Kennedy et al. 2007)
- China (Chan et al. 2007; Fu et al. 2006; Fu et al. 2003; Siu et al. 2007)
- the Netherlands (Elzen et al. 2007).

The effect of the CDSMP on exercise behaviour will be discussed in *Chapter Two*. Firstly, and before describing self-management and self-efficacy, a comparison of the CDSMP and cardiopulmonary rehabilitation is offered in the next section.

1.6 Programme Comparisons

The CDSMP replaced cardiopulmonary rehabilitation, the dominant traditional model for COPD management, in the hospital where this research took place. The aims, assumptions and content of each are compared in the following discussion.

1.6.1 Aims, Assumptions, Content and Process

1.6.1.1 Aims of the CDSMP and Cardiopulmonary Rehabilitation

The CDSMP aims to help people self-manage their chronic condition (Lorig 1996). These aims have similarities to those of cardiopulmonary rehabilitation where the overall aim is to maximise independent functioning (Abramson et al. 2006; Nici et al. 2007; Ries et al. 2007). A comparison reveals the CDSMP targets generic health-related behaviours, while cardiopulmonary rehabilitation focuses on condition-specific behaviours (Table 1).

Table 1: Comparison of Programme Aims

CDSMP Aims (Lorig, Sobel et al. 2001; Lorig, Sobel et al. 1999)	Cardiopulmonary Rehabilitation Aims (Abramson et al. 2006; Nici et al. 2007; Ries et al. 2007)
Assist patients in managing the medical aspects of their disease.	Follow a symptom-related action plan for exacerbations.
	Adhere to medication regimes.
	Use delivery devices properly.
	Adopt and maintain smoking cessation.
	Adopt and maintain an exercise regime.
Continue their roles in life.	Maximise independent functioning.
Recognise and regulate difficult emotions such as depression, fear and frustration.	Follow treatment of anxiety and depression.
Equip patients with skills to increase their confidence in managing their health-related problems.	Develop self-management skills.

1.6.1.2 Assumptions of the CDSMP and Cardiopulmonary Rehabilitation

In developing the generic CDSMP, Lorig and colleagues (Lorig, Sobel et al. 1999) describe underlying assumptions that relate to the person with the chronic condition:

- similar self-management problems and tasks are faced by people with different chronic conditions
- responsibility for the daily management of chronic conditions can be learnt by patients
- proficient self-managers will experience improved health while accessing fewer medical resources.

As well as these three main assumptions, an additional three relating to the programme are also noted (Lorig, Sobel et al. 1999):

- inexpensive and widely available programmes are desirable
- peers, non-health professionals with chronic conditions, can be trained to deliver a structured programme effectively
- both patients and professionals would find these trained peer leaders acceptable.

Training peer leaders as positive role models, and so informing self-efficacy by vicarious experiences, is the only one of the above assumptions for which a rationale is given in the literature. No assumptions for cardiopulmonary rehabilitation are reported in the literature.

1.6.1.3 Content of the CDSMP and Cardiopulmonary Rehabilitation

The course content of cardiopulmonary rehabilitation appears to differ from the CDSMP in that the guidelines do not emphasise teaching specific self-management skills such as setting goals and action plans, problem-solving and decision-making skills, which are identified elements of CDSMP (Table 2).

Table 2: Comparison of Programme Content

CDSMP Programme Content	Cardiopulmonary Rehabilitation Programme Content (Lecture series, with team member delivering the lecture noted)
Condition-specific information in the companion book	Heart and lungs: structure and function in relation to chronic heart and lung conditions (Physiotherapist)
Symptom management: anger, fear, frustration, depression; shortness of breath, fatigue, pain	Monitoring and responding to symptoms: relaxation, breathing exercises, managing breathlessness
Breathing exercises	Beginning an exercise programme (Physiotherapist)
Muscle relaxation	
Endurance exercise (discussion)	
Cognitive symptom management	
Communication skills	Living with heart and lung conditions: emotional and social impact, communication (Social Worker)
Advance directives for health care	
Working with and informing the healthcare team	
Medication usage: generic advice, specific information in companion book	Medications and delivery devices: condition specific (Pharmacist)
Healthy eating	Nutrition (Dietician)
Specific suggestions in the companion book	Activity modification (Occupational Therapist)
How to set action plans and problem solve	Not formally addressed

Note: The CDSMP course content is presented in comparison with cardiopulmonary rehabilitation and not as the content of the six individual CDSMP sessions. Cardiopulmonary rehabilitation is shown as the six sessions with the health professional who presented the lecture.

It is not clear whether cardiopulmonary rehabilitation is structured around problems defined by people with COPD and, as such, it does not appear to draw upon their lived experiences and expertise. The CDSMP is based upon issues relevant to people with chronic conditions. The precise content and organisation of the CDSMP is presented in a structured leaders’ manual (Lorig, Gonzalez & Laurent 1999), complemented by a resource book (LorigHolman et al. 1999). The educational content to be addressed in cardiopulmonary rehabilitation is suggested, but not precisely determined.

1.6.1.4 Comparison of Programme Process

The CDSMP covers six sessions of 2½ hours duration delivered once weekly over six weeks. There is no predetermined duration for cardiopulmonary rehabilitation. A recent survey of these programmes in Australia indicated that 57% run for eight weeks and with the exception of 2% ‘individual classes’, they are group-based (Australian Lung Foundation 2007). At the hospital where this research took place, the cardiopulmonary rehabilitation programme offered one session per week over seven weeks, with group-based sessions of two hours’ duration.

Both programmes have a focus on delivery of health-related information; however they differ with respect to the process of delivery (Table 3). Cardiopulmonary rehabilitation has a focus on participants receiving education from health professionals, while the CDSMP has a focus on participants sharing knowledge with each other. The latter process is facilitated by the leaders who ensure, with reference to the manual, that all points are covered in the discussion. The CDSMP process actively fosters the development of self-efficacy through role modelling, while cardiopulmonary rehabilitation offered previously at the hospital where the research took place did not deliberately target this. The other differentiating feature is the absence of supervised exercise with the CDSMP.

Table 3: Comparison of Programme Process

CDSMP Programme Process	Cardiopulmonary Rehabilitation Programme Process
Several topics per week, delivered in lecturettes with group brainstorming and interaction	One topic per week, delivered in a lecture format with discussion
Generic information supplemented by condition-specific information in a companion book	Generic information supplemented by condition-specific advice and written information
Leaders facilitate group discussion	Health professionals deliver knowledge
Structured peers learning from peers	Incidental peers learning from peers
Action planning, problem-solving, with guided feedback to the group	Aims, problem-solving and feedback provided on an individual basis
Self-efficacy development actively fostered	Self-efficacy development incidental
No supervised exercise	Supervised exercise

While both approaches facilitate the adoption of health-related behaviours, it will become evident in the following section that adopting health-related behaviours is an acknowledged self-management activity. The following section defines self-management, its related responsibilities and the suggested activities involved when self-managing.

1.7 Self-Management

Self-management is receiving increasing attention in the COPD-related literature. Revised guidelines and recent reviews refer to enhancing self-management as a strategy for people with COPD when incorporating health behaviours into daily life (Bourbeau, Nault & Dang-Tan 2004; Make 2003; Nici et al. 2007; Ries et al. 2007). The CDSMP aims to help people learn to self-manage. It is therefore relevant to this thesis to discuss self-management in this chapter. However, as it will become evident when drawing comparisons between the CDSMP and comprehensive cardiopulmonary rehabilitation, reports of 'self-management' may either encompass various activities and responsibilities or have a singular focus on symptom management.

People with chronic conditions develop ways of managing their lives, irrespective of the healthcare interactions they may or may not experience (Taylor & Bury 2007). These coping strategies have been acknowledged by others (Battersby et al. 2003; Clark 2003; Clark et al. 1991; Corbin & Strauss 1988; Kralik et al. 2004; Lorig 2003). The strategies are often included in an operational definition (Battersby et al. 2003) and, as such, emphasise the 'managing' aspects of self-management. This emphasis is reflected in studies reporting health status and behaviours (Fu et al. 2003; Siu et al. 2007; Swerissen et al. 2006). While adopting health-behaviours is one of the acknowledged self-management activities, self-efficacy is also a measured outcome, bringing into focus the 'self' in self-management (Walker et al. 2003). This works in concert with the 'managing' aspects, both components being integral to a definition of self-management.

1.7.1 Self-Management: Definition, Responsibilities and Activities

The literature suggests commonalities with respect to managing life with any chronic condition, and this is useful in defining self-management. Published work indicates

that people with chronic conditions undertake responsibilities and engage in activities related to three major areas of their lives, first identified by Corbin and Strauss (1988) as being medical issues, quality of life and emotional impact

Others have added to this work by reviewing the self-management activities of older adults with five chronic conditions: heart disease, asthma, COPD, diabetes and arthritis (Clark et al. 1991). They identified common activities in which effective self-managers engaged (shown in Table 4), leading them to conclude that knowledge is not the main component for effective self-management. This work was later supported by a qualitative analysis of people with arthritis, wherein participants placed less emphasis on the acquisition of knowledge and more on the processes of managing (Kralik et al. 2004) .

Table 4: Responsibilities and Activities Listed by Authors

Author(s)	Self-Management Activities
Corbin & Strauss (1988)	<i>Managing the medical aspects</i> of the condition <i>Dealing with the emotional impact</i> of living with a chronic condition <i>Adapting behaviours</i> to maintain a meaningful quality of life
Clark et al. (1991)	<i>Monitoring symptoms</i> , physical and emotional aspects and responding appropriately <i>Managing relationships</i> and the impact of chronicity on one's psychosocial role <i>Undertaking health-related activities</i> (medication use, diet, exercise, relaxation, smoking cessation) to manage the condition <i>Interacting</i> with providers of healthcare
Lorig & Holman (2003)	<i>Monitoring and managing</i> the daily impact of a chronic condition on one's life and making informed decisions in response to this <i>Making short-term action plans</i> in order to adopt new <i>health-related</i> behaviours <i>Working in partnership</i> with healthcare providers, discussing the pattern of the condition and treatment options <i>Following problem-solving steps</i> of identifying the problem then suggesting, selecting and implementing a possible solution <i>Utilising resources</i> and knowing where and how to seek assistance
Battersby et al. (2003)	<i>Monitoring and responding</i> to the symptoms and signs of condition(s) <i>Managing</i> the physical, emotional and social impact of condition(s) <i>Engaging in health-related activities</i> <i>Negotiating</i> a plan of care with healthcare providers <i>Knowing</i> the condition and its treatment options
Kralik et al. (2004)	<i>Monitoring</i> the condition and its symptoms and recognizing the limitations these placed on activities of daily life; <i>Engaging in adaptive behaviours and social interactions</i> <i>Re-interpreting</i> a self-identity <i>Planning for, prioritising and pacing activities</i> , while balancing the pros and cons in decision-making

Lorig and Holman (2003) have drawn on the work of the previous researchers incorporating their concepts into an expanded set of what they term 'self-management skills' (Table 4). This is achieved in a context to which the authors refer as 'self-tailoring': using these core skills and applying them to fluctuating individual needs as appropriate. These skills are incorporated into the CDSMP (Lorig, Gonzalez & Laurent 1999). Table 4 also shows the self-management activities supported by

Battersby and colleagues (2003). However, these authors do not mention self-management occurring within the self-tailoring context referred to above.

1.7.1.1 A Synthesis of Self-Management Definition, Responsibilities and Activities

Self-management is a term widely used in the healthcare literature and recently in government policy. Despite this widespread use, there appears to be no universally accepted definition of self-management (Barlow et al. 2002). The term is also used interchangeably with self-determination, self-help or as it is also known, self-care. Therefore a consideration of the definition of these terms is necessary as it points to subtle differences: 'self-determination' implies acting with free will; 'self-help' suggests providing for or improving oneself and 'manage' relates to coping with issues (Tulloch 1995). 'Management' therefore does not necessarily imply by choice or effecting improvement. This distinction is of note for people with chronic conditions including COPD who have no choice but to manage their lives in one way or another, the only question being *how* they manage (Lorig & Holman 2003).

How a person perceives of, thinks of and feels about themselves influences the 'managing' strategies they will employ when coping with a chronic condition. This points to a duality when considering the term 'self-management' and brings into focus the 'self' in self-management (Walker et al. 2003). For this thesis, the duality is incorporated in the definition of 'self-management' and is accompanied by acknowledged responsibilities and activities.

Self-management has been described as controlling or reducing the effect of living with a chronic condition on physical and psychosocial health (Clark et al. 1991) or as disease management by the patient (Clark 2003). These authors emphasise that this definition refers to the strategies used to manage a chronic condition. When arriving at a definition of self-management, Clark notes the need to differentiate between self-management (disease management by the patient) and self-regulation, which she defines as the process by which the person derives their self-management strategies. A model of self-regulation describes the continuous and reciprocal process of observations, judgments and reactions in which a person engages while attaining their goals (Bandura 1978, 1997; Clark, Gong & Kaciroti 2001; Schwarzer 2001).

Integral to this is the degree of ‘confidence’ (self-efficacy) and importance assigned to the goal by the individual (Bandura 1986).

In summary, self-management in this thesis is defined as a dynamic process incorporating an individual’s capability and confidence to undertake responsibilities and to engage in activities that enable them to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and their medical, emotional and social domains.

Drawing together the work of the above authors (as shown in Table 4), it is suggested that in order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities. Fulfilling responsibilities requires the undertaking of specific activities (Table 5).

Table 5:Self-Management Responsibilities and Activities

Self-management Responsibilities	Self-management Activities
<i>Respond to the impact</i> of a chronic condition on one’s overall health, incorporating a sense of self and the physical, mental, social, emotional and spiritual aspects of health	<i>Having awareness of thoughts</i> pertaining to the self, and <i>prioritising, planning and pacing</i> to maintain roles in life
<i>Monitor and respond to the symptoms</i> of the chronic condition	<i>Following a symptom-related action plan</i> that requires knowledge of the condition and its symptoms, the skill to monitor and interpret them, and to follow an agreed plan of action. In this way the person self-regulates.
<i>Engage in behaviours</i> to promote good health	<i>Having an understanding of health-related behaviours</i> and how these relate to individual circumstances.
<i>Utilise resources</i> , both internal (personal) and external (various sources)	<i>Seeking and implementing information</i> concerning health in general and in health-related behaviours
<i>Work in partnership</i> with healthcare providers and carers.	<i>Communication and decision-making</i> skills to effectively work with carers and healthcare providers.
<i>Learn core self-management skills</i>	<i>Setting goals with action plans</i> to achieve those goals <i>Problem-solving skills</i> (problem identification, seek, implement and evaluate possible solutions).

As previously noted, the CDSMP is one intervention aiming to promote the adoption of health-related behaviours and to facilitate self-management of chronic diseases. Self-efficacy has been implicated as an agent in the regulation of human behaviour

(Bandura 1986), including exercise, an area of enquiry in this thesis. As such it is important and will be discussed in the following section. The construct of self-efficacy underpins the CDSMP (Lorig, Gonzalez & Laurent 1999) and is receiving increasing attention in the cardiopulmonary rehabilitation-related literature (Bourbeau, Nault & Dang-Tan 2004).

1.8 Self-efficacy

Self-efficacy is a construct of a broader psychosocial theory, first known as social learning theory when published in Bandura's seminal text in 1977 (Bandura 1977), and now known as social cognitive theory. This theory draws together the reciprocal interaction between personal, social and environmental factors in the regulation of human behaviour (Bandura 1986). These variables are suggested as determinants of exercise behaviour (King 2001; Sherwood & Jeffery 2000; Speck 2002) that can be influenced at the individual level of a socio-ecological model of health (Sparling et al. 2000). Self-efficacy has been suggested as a mediator and an outcome of exercise behaviour (McAuley & Blissmer 2000). The following discussion refers to the CDSMP and people with COPD, demonstrating how self-efficacy contributes to behaviour adoption or maintenance. As a first step, the meaning of self-efficacy will be explored.

1.8.1 Meaning of Self-efficacy

1.8.1.1 Definition

Individuals make choices or set goals about what they will do in life and how they are going to do this. Fundamental to any behaviour change is the intention or the motivation to change, selecting a goal with the expectancy that the goal is attainable and the outcome valued (Bandura 1997). In addition, the *perception* of one's ability to achieve an outcome influences the goal chosen, the amount of energy expended in its pursuit and perseverance in the face of barriers (Bandura 1997). For example, a man with severe COPD has a goal of wanting to be able to join his family's moderate walking activities when on holiday. It is important to him to be able to 'keep up' with his family. He expects that as his fitness improves he will achieve his goal. He plans to start walking around his office, progress to outdoors, and finally walk along the beach near his home. In this way he envisages joining the family activity on holiday.

His goal is *important* to him, providing the initial motivation for adopting exercise. He *expects* his efforts will result in increased fitness, and he *believes* in his ability to do this.

The term given to this perception or belief that one 'has what it takes' is self-efficacy. Self-efficacy is thus a belief in one's ability to achieve goals, organising and undertaking the necessary action to manage different situations in life, in order to reach the desired outcome (Bandura 1986). The processes involved in setting and pursuing goals are discussed in the following section.

1.8.2 Setting Goals

As people adopt behaviours to achieve their goals they initially observe and make judgments about their own behaviour, implement a course of action to reach the goal, then draw conclusions as to the outcome of the experience. In other words, they monitor or self-regulate their behaviour (Bandura 1978, 1997; Clark, Gong & Kaciroti 2001; Schwarzer 2001). With goal attainment, the person's belief in their ability to achieve their goals is likely to be strengthened, that is, their sense of self-efficacy will be enhanced. Once a robust sense of self-efficacy is established, generalisation to related activities can occur (Bandura 1986).

Setting a goal in and of itself does not serve as a motivational force for behaviour change. People must first intend to exercise, for example, and they require a standard by which to judge their endeavours, such as achieving recommendations for daily physical activity. Self-efficacy beliefs act with the goal by influencing the choice of goal, the effort expended in pursuing the goal, and whether the expected outcome will be realised (Bandura 1998). Specific properties of goals contribute to self-efficacy and facilitate motivation to persist with the intended behaviour (Bandura 1977, 1986). These properties are:

- Goal specificity
- Goal level
- Goal proximity

1.8.2.1 Goal Specificity

Clear specific goals offer a framework for feedback or personal evaluation of the behaviour in question. This helps to regulate the effort required to achieve the goal (Bandura 1986) and provides direction and motivation to the effort (Bandura 1997). In addition, the goal has greater influence if it is personally relevant to the individual, providing the motivation to self-regulate and so develop strategies to self-manage (Clark et al. 1991; Clark, Gong & Kaciroti 2001). Self-efficacy is deemed to be behaviour-specific; therefore goals need to be defined in terms of behaviours and may be approached by specifically formulating a plan of action that further delineates the steps to be taken. Behaviour-specific action plans are formulated by CDSMP participants addressing goals they want to pursue, rather than goals prescribed by others (Lorig, Gonzalez & Laurent 1999). This point is pertinent to this thesis, because in clinical practice emphasis is often placed upon an exercise prescription *given to* the person with COPD. *Inviting* the participant to define their own exercise parameters is not a feature described in cardiopulmonary rehabilitation programmes.

1.8.2.2 Goal Level or Challenge: 'Setting the Bar'

How high or low to 'set the bar' is a question for people when setting the parameters of their goals. For exercise, these parameters would pertain to frequency, intensity and time or duration. A number of views of other researchers concerning goal level have been summarised by Bandura (1986, p. 473): 'When goals are set unrealistically high, most performances prove disappointing. Strong effort that produces repeated failure weakens perceived self-efficacy, thereby reducing motivation to perform the activity.' Similarly, if the 'bar' is set too low and goals are achieved with minimum effort people are inclined to infer low self-efficacy, and perseverance in the face of adversity is likely to be compromised (Bandura 1986).

Determining the level of the goal is an important issue for people with COPD, especially with respect to physical activity. Many are compromised by breathlessness and have reduced their physical activity level in order to avoid breathlessness, getting caught in a downward spiral of decreasing activity and increasing breathlessness on exertion (Bellamy, Booker & Fardy 2003). Many of these people require guidance so that the 'bar' is set at a level whereby they can progress their exercise without so

much breathlessness that they give up. In defining action plans during the CDSMP, participants nominate frequency, intensity or duration of the activity with an emphasis on ‘setting the bar’ at an achievable level (Lorig, Gonzalez & Laurent 1999).

1.8.2.3 Goal Proximity

Immediate sub goals directed towards attaining a distal goal are purported to be more effective at influencing current behaviour (Bandura 1977, 1986). Based on this work, setting a smaller sub-goal to walk to the letter box ‘this week’ would be a sub-goal of intending to walk to the shop by the end of the month, which in turn could be directed towards the overarching goal of wanting to increase fitness. Each sub-goal can be approached by formulating a plan of action, as noted above.

As people strive towards their goals they draw upon four main sources of information that facilitate the development of self-efficacy (Bandura 1977). These sources are described in the following section.

With goals defined, what contributes to self-efficacy development?

1.8.3 Sources of Self-efficacy Information

The sources that influence the development of self-efficacy are:

- mastery experiences
- vicarious experiences
- social persuasion
- physiological and emotional states. (Bandura 1977)

1.8.3.1 Mastery Experiences

Enacted or mastery experiences are the most influential of the sources of self-efficacy information. Mastery experiences refer to the personal experience of accomplishing a task. This requires self-regulation as described above, and relates to the goal level. While individuals master their behaviours, they learn that barriers can be overcome by persevering. In this way, robust self-efficacy for the behaviour is developed (Bandura 1998).

During the CDSMP, participants have the opportunity to implement, evaluate and practise specific skills such as identifying and solving problems and setting action plans (Lorig, Gonzalez & Laurent 1999). Through weekly action plans, behaviours practised during the CDSMP may be reinforced. Detailed behaviour-specific intended plans of action have been referred to as ‘implementation intentions’ (Gollwitzer 1999) and receive support from other authors as an important mediator and predictor of health-related behaviour change (Sniehotta, Scholz & Schwarzer 2005). As people set and complete action plans their mastery for the activity increases, augmenting their self-efficacy for that behaviour (Bandura 1998). This in turn promotes the setting of further goals and action plans via a reciprocal interaction.

1.8.3.2 Vicarious experiences

A second source of self-efficacy information is vicarious experiences. Vicarious experiences describe learning through role modelling or by observing similar others (Bandura 1977). The more similar the perception, the greater the influence of the model on the individual (Bandura 1997, 1998). Self-efficacy is strengthened when people observe the success of similar others (Bandura 1986; Schunk 1987). Conversely self-efficacy is damaged if role models are observed to fail despite their best efforts (Brown & Inouye 1978). Models who persevere in the face of adversity may, through vicarious experiences, exert a greater positive effect than the behaviour being modelled (Bandura 1997).

Role models are extensively referred to in the CDSM literature (Fu et al. 2003; Lorig, Sobel et al. 2001; Lorig, Sobel et al. 1999; Siu et al. 2007). It is this perceived similarity to models that led to the training of peer leaders — that is, non-health professionals with a chronic condition — for the initial Arthritis Self-Management Program (Lorig 1982, 1986, 1995; Lorig & Gonzalez 1992) followed by the CDSMP (Lorig, Sobel et al. 1999). However, Lorig and colleagues later found no differences in programme outcomes when led by peers only, professionals only or a peer and a professional working together. It was not stated whether the professional leaders had a chronic condition or not (Lorig Sobel et al. 2001). Additionally, Chinese researchers demonstrated successful facilitation of CDSMPs by health professionals

or peer leaders (Fu et al. 2003). These findings are important for this thesis because health professionals trained as leaders to facilitate the CDSMP for this study.

Identifying with similar others has also been conceptualised as ‘social comparison’ in that people tend to evaluate their abilities through comparison with those perceived to be like themselves (Festinger 1954). ‘Direction’ has subsequently been added to the comparison with others: downward social comparison being comparison with those perceived to be worse off and upward social comparison being comparison with those perceived to be better off. The authors suggested that either ‘direction’ may serve as a motivational source (Buunk et al. 1990).

1.8.3.3 Positive social persuasion

The third source of self-efficacy information is positive social persuasion. Receiving encouragement for individual self-management efforts through guided feedback sessions and group support is an integral part of the CDSMP. When an individual is constantly assured that they are capable of success, they are likely to strive harder to achieve the goal and self-efficacy is strengthened (Litt 1998; Schunk 1987). It is important that positive social persuasion encourages people to perceive improvements as personal successes, as opposed to winning over others (Bandura 1997, 1998). However, if one is told that they lack the ability to succeed then they are likely to give up or avoid difficult situations. Negative verbal reinforcement has a greater effect on self-efficacy than positive affirmations. Interestingly, social persuasion has not been identified as a specific component of other self-management strategies (Barlow et al. 2002; Chodosh et al. 2005; Newman, Steed & Mulligan 2004; Warsi et al. 2004; Weingarten et al. 2002).

1.8.3.4 Dealing with emotional states and reinterpretation of symptoms

Physiological and emotional states influence self-efficacy, depending how the individual perceives the state of arousal (Bandura 1997, 1998). Interpreting these states in a positive way is the fourth way of strengthening self-efficacy. A negative interpretation of the body’s response to stress, especially when interpreted as physical debility, has a negative effect on self-efficacy (Ewart 1992).

This is a strategy specifically used for increasing self-efficacy in the CDSMP (Lorig, Sobel et al. 2001). Many interventions aimed at helping people manage life with chronic conditions incorporate relaxation techniques and information to help people deal with symptoms and difficult emotions such as stress, anger or depression (Barlow et al. 2002). During the CDSMP, participants have opportunity to practise various forms of relaxation, distraction or other cognitive-based techniques for managing symptoms. With reference to a 'symptom cycle', they consider how their symptoms may have causative factors other than the condition (reinterpretation) and then how they might intervene to manage these symptoms (Lorig, Gonzalez & Laurent 1999)

Mood has also been implicated in perceived self-efficacy. Kananagh and Bower demonstrated that inducing a positive mood through recollection of positive behaviours promoted self-efficacy not just for that behaviour, but for a range of competencies. The reverse held for low mood (Kavanagh & Bower 1985). This strategy is not used specifically during the CDSMP; however, this observation has particular relevance for people with COPD, many of whom experience depression as a comorbidity (Yohannes, Baldwin & Connolly 2000). It could be a useful adjunct to helping people with COPD manage the limitations placed upon their lives. Bandura concludes that by improving physical ability, reducing stress and reinterpreting symptoms, self-efficacy is enhanced (Bandura 1977, 1986).

As noted earlier in this chapter, self-efficacy is also a construct incorporated in the transtheoretical model of behaviour change. This is described in the section below with reference to exercise adoption.

1.8.4 Self-efficacy and the Transtheoretical Model of Change

The transtheoretical model of behaviour change addresses a person's perception of a need to change or readiness to embrace change (Nigg et al. 1999; Prochaska 1984; Prochaska & DiClemente 1983; Prochaska, DiClemente & Norcross 1992; Prochaska & Velicer 1997; Velicer et al. 1998). Reference is frequently made to this model by health professionals when discussing adoption of health behaviours (Lidner et al. 2003). Some have suggested that the CDSMP is more suited to those who are ready to take action to make behaviour change (H. Lidner 2005, pers. comm., 10 May). Whether the transtheoretical model is an appropriate explanatory model for adoption

of exercise for people with COPD following CDSMP attendance does not appear to have been reported in the literature. Therefore, stage of change for exercise was measured pre and post CDSMP, as outlined in *Chapter Three*.

1.8.4.1 The Stages of Change

As a prelude to a discussion of the utility of the transtheoretical model with respect to exercise behaviour, the stages of change are summarised below. As people progress through the stages, the decisional balance moves in favour of the positives and self-efficacy for the behaviour is purported to increase while temptation decreases (Velicer et al. 1998). The stages are explained below.

- Precontemplation is the stage where individuals are either unaware that change is necessary or have no intention of changing behaviour, such as adopting exercise, within the next six months. Such people may desire to change but do not intend to do so. They are often labelled as resistant, unmotivated or in denial by some health practitioners.
- Contemplation is the stage where people are intending to make behaviour change within the next six months but have not committed themselves to action, such as beginning a regular exercise regime.
- Preparation is the stage where people have the intent of taking action to change behaviour in the next month. In the preceding year they may have had unsuccessful attempts at behaviour change or may have made some changes but not reached the final target.
- Action is the stage where people have made specific changes to their behaviour within the last six months and have reached a consensus target for that behaviour, for example, undertaking regular exercise according to recommendations.
- Maintenance is the stage where individuals continue the behaviour changes they have made and persevere to prevent relapse.
- Termination is the final stage where people have altered their behaviour and have no fear of relapse. Temptation is minimal and self-efficacy maximal. For the adoption of healthy behaviours such as exercise, lifetime maintenance is probably a more realistic term.

Behaviour change does not occur quickly (Prochaska 1991) and according to the model, people making change are not evenly distributed across the stages. A generalisation of stage distribution is precontemplation 40%, contemplation 40% and action 20% (Prochaska & Velicer 1997). This indicates that a large proportion of people advised to make health-related behaviour change, such as adopting exercise, may not be ready to take action. Whether this is true for the CDSMP is an area of inquiry in this research. Additionally, whether the CDSMP, a non-staged intervention, results in stage progression for exercise is also explored in this thesis.

1.8.4.2 The Transtheoretical Model and Exercise

There is a considerable body of research concerning the transtheoretical model and exercise behaviour, supporting an increase in self-efficacy for exercise with stage progression (Fahrenwald & Walker 2003; Guillot et al. 2004; Marcus, Banspach et al. 1992; Marcus, Selby et al. 1992; Nishida et al. 2003; Ronda, Assema & Brug 2001; Sarkin et al. 2001; Wakui et al. 2002). This has led to stage-matched interventions, with preliminary support in the exercise arena provided by an early study of a cohort of 236 adults aged 18 to 82 who progressed along the stage of change continuum following the intervention (Marcus, Banspach et al. 1992). In more recent years these observations have not been replicated in other trials. Two separate cohort studies comparing a staged and non-staged exercise intervention demonstrated no significant difference between the two for mature-age adults attending a physiotherapy out-patients department (Sheedy et al. 2000) and no change in self-reported exercise levels or in self-efficacy for middle-age adults attending a health check (Naylor et al. 1999). However, results showed progression in the stages of change, leading Naylor and colleagues (1999) to conclude that no approach was better than any other.

In a systematic review of 37 randomised-controlled trials of interventions based on the transtheoretical model of change, seven of which were exercise-related, the authors concluded that there was insufficient evidence to indicate that any of the stage-based interventions were any better than non-staged interventions, no intervention or to usual care (Riemsma et al. 2002). Adams and White concluded that while stage-based interventions for adoption of physical activity may be effective in the short term, they appear not to be so in the longer term (Adams & White 2003;

Adams & White 2005). If non-staged interventions such as the CDSMP result in stage progression, then the utility of stage-based interventions for physical activity/exercise might be called in to question.

Perhaps it is not so much whether the intervention is stage-based or not, but whether the intervention facilitates the translation from behavioural intention to actually undertaking the behaviour (exercising) that is important. This research will investigate the effect of the CDSMP with or without supervised exercise on both exercise self-efficacy and stage of change for exercise.

1.9 Contribution of this Thesis

This study aims to make a contribution in a number of areas explained below.

- First, by drawing together the results of a rigorously controlled intervention aimed at obtaining the highest level of evidence possible in a clinical setting, the study informs current clinical practice and policy within the hospital.
- Second, this study has methodological value. The above objective is achieved by investigating the intervention with a mixed methods approach: utilising quantitative outcomes and ‘marrying’ this with the voices of the participants by employing methods of qualitative enquiry. Enriching quantitative data with qualitative findings is critical for medical research involving patients if health professionals are to avoid a ‘self-imposed institutionalized autism that is a denial of the importance of story’ (Bleakley, 2005, p. 39).
- Third, the study adds to the evidence-base for the CDSMP. Exercise is recommended for its health benefits for the general population and for those with COPD in particular. Evidence-based guidelines for COPD management suggest that exercise sessions be supervised, yet the CDSMP does not include supervised exercise. There is scant reference to the effect of supervised exercise with the CDSMP in the literature. If the CDSMP is to be offered to people with COPD instead of traditional approaches that include supervised exercise, it is essential that the effect of the addition of supervised exercise with CDSMP on exercise-related outcomes be measured. This research will address this issue.

- Fourth, behaviour change may be challenging. Behaviour change theories frequently offer explanations as to the adoption of behaviours such as exercise. This research enables the evaluation of a different approach to care of people with COPD: the CDSMP, which is underpinned by behaviour change theory and which emphasises a partnership with the patient. By listening to the voices of participants, this thesis makes a theoretical contribution and suggestions for engagement with participants in the field of chronic disease self-management.
- Fifth, governments are assessing the evidence and making decisions about future funding for self-management approaches. There are calls for more involvement of health professionals. There are calls to reach those who do not 'self-refer'. This study addresses these two issues. Health professionals were trained to facilitate the CDSMP. The study drew its participants from referrals from primary and secondary care, and did not utilise advertisements to attract volunteers, thereby extending the reach of the CDSMP to a potentially less well group of people.

1.10 Thesis Aim and Primary Research Questions

The aim of the thesis is to explore the effect of supervised group exercise offered in conjunction with the Stanford CDSMP for people with COPD. The first research question arising from clinical practice and from a review of the literature, which will be discussed in the following chapter, is:

- What would be the effect of supervised exercise on physical capacity and exercise behaviour when offered with the CDSMP?

The hypothesis for this research is: the addition of supervised exercise to the CDSMP will result in a greater increase in distance walked by at least 54 metres, the currently accepted minimal clinically important difference (Redelmeier et al. 1997).

COPD is one chronic condition that exacts a toll on the health of people living with this disease. As it will be explained in *Chapter Three*, quantitative outcome measures provide valuable information upon which to make clinical judgments. Arguably, they do not assist in understanding what enables or constrains behaviour change from the

participants' perspectives. Neither do they reveal what the participant values in healthcare interactions and deems to be important for interventions. Qualitative methods of inquiry are well situated to do this. Hence a second research question was posed:

- What is the lived experience of people with COPD who attend the CDSMP with or without supervised exercise?

To investigate these different questions and so inform clinical practice objectively and from a participant perspective, a mixed methods approach was utilised. This research will address the questions and discuss them in the following chapters, which are organised as described below.

1.11 Organisation of this Thesis

In *Chapter One, Introduction*, the rationale for this research is explained. The increasing prevalence and associated burden of chronic conditions, one of which is COPD, and the growing field of self-management of chronic conditions provides the context of this research. Exercise is recognised as a major modifiable health-related behaviour (Joint Advisory Group on General Practice and Population Health 2001). Theories to explain how its adoption might be influenced are presented. This chapter provides opportunity to explore the benefits of exercise conferred on people with COPD. Comparisons are drawn between the Stanford CDSMP and comprehensive cardiopulmonary rehabilitation.

Chapter Two, Literature Review, brings together literature exploring a meaning of health as a prelude to differentiating between acute and chronic conditions. This discussion is integral to the thesis as it demonstrates why management of chronic conditions demands a different approach to that of acute episodes of care. Studies quantitatively reporting the effect of the CDSMP on exercise are reviewed. Qualitative studies are discussed. Exercise self-efficacy in people with COPD and chronic disease self-management interventions for this population are considered.

The approach employed to investigate the research questions is expanded upon in *Chapter Three, Methodology*. The study protocol is presented in detail. The primary outcome measure, the six-minute walk test (Guyatt et al. 1985), is described as well

as a suite of secondary outcome measures. The rationale for their selection is given. The qualitative method of inquiry and the steps followed in the iterative analysis of the semi-structured interviews of a purposefully selected sample of 20 participants are explained.

Chapter Four, Quantitative Research, contains the results of the outcomes from the 84 people who enrolled in the study. Statistical analyses were conducted on the outcomes measured pre and post participation in the CDSMP with or without supervised exercise to ascertain the effect of the exercise intervention.

Chapter Five, Discussion of Quantitative Outcomes presents a discussion of the quantitative research. An additional element of triangulation, provided by reporting a comparative quantitative analysis of the participants interviewed with the sample from which they were drawn, is also reported in this chapter.

The findings are presented in *Chapter Six, Qualitative Research*. Thematic analysis explored the lived experience of people with COPD attending the CDSMP and the experience of supervised exercise, thus enriching the quantitative data.

Chapter Seven, Discussion of Findings, contains the discussion related to the qualitative enquiry.

Chapter Eight, Conclusions and Implications, draws together the quantitative and qualitative arms of the study. Conclusions are arrived at and implications for practice and future research suggested.

1.12 Chapter Summary

In summary, this background introduction has situated the research for this thesis in a context of increasing prevalence and burden of chronic disease, including COPD, and an increased recognition of self-management interventions as a way of helping people to manage the daily impact of life with a long-term health condition. The Stanford CDSMP is an example of a self-management intervention that replaced the more traditional cardiopulmonary rehabilitation programme at an Australian hospital. Exercise is recognised as conferring substantial health benefits for people with COPD. Traditionally, cardiopulmonary rehabilitation programmes have encouraged

the adoption of exercise, recommending initial supervision of exercise. However, there is no supervised exercise with the CDSMP.

Although not new, there is a shift in patient care to a focus on healthcare providers and patients working in partnership. Patient-centred healthcare has been gaining in importance. This concept is integral to this thesis as it allows for the development of a framework that draws together components of self-management, theories of personal behaviour change and the facilitation of self-efficacy and self-regulation of behaviour. This will be discussed further in this thesis.

Implementing the results of this study will have involved a partnership with participants and health professionals. The participants' needs and preferences will have been acknowledged and informed shared decisions made. As a prelude to detailing the methods used to investigate the effect of supervised exercise with the CDSMP, the literature was appraised to situate the thesis in the current field of chronic disease self-management. This is discussed in the following chapter.

2

CHAPTER TWO:

LITERATURE REVIEW

2.1 Introduction

As noted in *Chapter One*, chronic disease management approaches are being advocated by the Australian and Tasmanian state governments as models of healthcare for people with long-term health conditions, directly in response to a transition from a health scene dominated largely by acute conditions to one in which chronic conditions are gaining dominance (McCallum 2000).

In the preceding chapter health was defined as a dynamic entity. It follows that a person would experience varying degrees of health, depending on their particular circumstances and how they perceive the impact on their lives. For people with COPD, health may be affected by an acute worsening of the condition (Bellamy, Booker & Fardy 2003; MacNee & Rennard 2004), or particularly by the day-to-day impact of breathlessness on daily life (Fraser, Kee & Minick 2006). This review will consider the differentiating features of acute and chronic conditions, with reference to COPD, specifically what factors differentiate between an acute episode and the ongoing impact of the chronic nature of COPD, and what implications this has for care.

The benefits of exercise for people with COPD were explained in *Chapter One*. In this chapter, what constitutes sufficient daily exercise and studies reporting the effect of the CDSMP on self-reported exercise will be reviewed. In addition, qualitative enquiry concerning the participant experience of the CDSMP will be discussed.

Chronic disease self-management (CDSM) approaches are assuming significance as interventions for people with long-term health conditions such as COPD. CDSM

interventions will be referred to in a context of self-management support and discussed with reference to the CDSMP and the COPD literature.

2.2 Differentiation between Acute and Chronic Conditions

People with COPD experience frequent acute exacerbations of their underlying condition (Bellamy, Booker & Fardy 2003; MacNee & Rennard 2004). By definition, and in common with other acute presentations of illness, the onset may be rapid, the exacerbation may be critical and life-threatening (Tulloch 1995) and appropriate treatment should be implemented quickly by a health professional (Lorig 1996). Patients may be too unwell to be able to participate in making decisions about their treatment. While not losing sight of the person with the condition, a medical model responds to this by focusing on the condition *with which* the patient presents (Nair & Finucaine 2003) and is most appropriate for acute presentations that may require immediate life-saving measures or prompt action to prevent further complications.

Conversely, the onset of COPD, like many chronic conditions, is usually gradual and develops over years due to incremental damage from cigarette smoke and other noxious substances (Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2007). Like other chronic conditions it may be difficult to diagnose in the early stages. It may follow an unpredictable course of indefinite duration, and a cure does not exist (Lorig 1996). By definition, chronic conditions persist for at least three to six month's duration (Australian Institute of Health and Welfare 2001). They have repeated health impact, often requiring ongoing modifications to lifestyle and continued contact with health professionals (Hoffman, Rice & Hai-Yen 1996). However, such interactions represent only a fraction of the time spent managing the condition on a daily basis. Thus the daily impact on the lives of those who live with long-term health issues is emphasised (Hoffman, Rice & Hai-Yen 1996) and the focus shifts from the disease process to the person living *with* the condition (Nair & Finucaine 2003).

Whereas acute illness may bring a temporary interruption to a person's life, the experience of chronic illness such as COPD may change a person's life irrevocably. In contrast to managing acute conditions, people with COPD must manage ongoing

behaviour change such as taking medications, addressing diet and physical activity (Bellamy, Booker & Fardy 2003). They deal with difficult emotions, symptoms and exacerbations, mood alterations, limitation of daily activities and social and family upheaval (Guthrie, Hill & Muers 2001; Seamark, Blake & Seamark 2004). These stressful emotions and losses may result in a spectrum of depressive and anxiety-related symptoms.

Such losses may result in the individual with COPD experiencing a loss of perceived personal control over their lives, an observation made by others with respect to older people with disability (Kempen et al. 2005). Personal control describes how successfully a person perceives they can achieve positive outcomes and avoid negative effects in their lives (Petersen & Stunkard 1989). The perception of personal control is said to have a beneficial effect on health, wellbeing and motivation (Chipperfield, Perry & Menec 1999). Conversely, loss of perceived personal control may lead to depression, helplessness, poor health and increased suffering (Chipperfield, Perry & Menec 1999; Janis 1983). Approaches such as the CDSMP, which aim to foster self-efficacy development by building a belief in one's ability to achieve goals, may act to enhance perceived personal control. As will be discussed later, self-efficacy is a measured outcome of the effectiveness of the CDSMP, but perceived personal control does not appear to have been measured previously.

The sociological literature refers to the impact of a chronic condition on the lives of people as a 'biographical disruption' (Bury 1982), or an 'altered trajectory' (Corbin & Strauss 1987). Some view the impact as a loss of self (Charmaz 1983). Whatever term is used, the change is acknowledged to have an impact on self-concept (Bury 1982) and self-esteem (Kralik 2002) resulting in a redefining (Corbin & Strauss 1987) or a re-evaluation (Charmaz 1987) of how people perceive themselves. Ultimately the impact of COPD is a disruption of the person's perception of health and wellbeing (Arnold et al. 2005).

What can individuals with COPD do so that they might attain the best possible health? As explained in *Chapter One*, exercise is now seen as a cornerstone of the interventions offered to people with COPD (Nici et al. 2007), and is the intervention evaluated in this research. What constitutes 'sufficient' exercise will now be addressed.

2.3 *'Sufficient' Exercise*

Clear national guidelines now exist to define the frequency, intensity, time, and type of physical activity necessary to benefit health. It is recommended that people be physically active on all or most days of the week (frequency) at a moderate pace (intensity) to accumulate 30 minutes (time) of aerobic activity (type) as a minimum goal for health benefits (Australian Government Department of Health and Aging 2005; United States Department of Health and Human Services 1996). As this recommendation for minimum levels of physical activity is 'for health benefits', for this thesis the term 'physical activity' defined in this way will refer to 'exercise'.

The Australian Institute of Health and Welfare (AIHW) has provided clarity to the guidelines with 'most days' being defined as '5 days' of the week (Australian Institute of Health and Welfare 2003). 'Moderate-intensity' is defined as sufficient to cause an increase in respiratory and heart rates, but not so that puffing and panting results. Such activity may be incorporated into domestic tasks such as housework and gardening, into occupational activities, for transport such as walking or cycling instead of taking a bus or car ride, and into leisure time activities such as sport and recreation (World Health Organization 2003a).

Accumulating 30 minutes of moderate intensity exercise in, for example, 10-minute increments, is now acknowledged as conferring similar health benefits as one continuous session (United States Department of Health and Human Services 1996). For people with COPD, accumulating 30 minutes as 'bites' of moderate exercise during the day would be more feasible, in that for many of these people breathlessness is an issue and continuous longer sessions are not possible. The CDSMP advocates action plans defined and implemented by the participant who may elect to exercise, rather than an externally imposed 'exercise prescription'. Whether attending the CDSMP and whether the addition of supervised exercise has an impact on self-reported levels of physical activity is an area of enquiry in this research.

In addition to accumulating bites of exercise with respect to time, if general daily activities are performed at least to a moderate intensity with the aim of maintaining or improving health, then such activities — be they domestic, leisure or occupational — would be considered to be exercise. In this way, 'doing exercises' might be

perceived as less onerous for those who are already compromised in their physical capacity.

In summary, a sufficient minimum level of exercise is defined as accumulating 30 minutes of moderate intensity physical activity on all or at least 5 days of the week. With the guideline established, the question arises whether individuals are exercising to recommended levels on a daily basis.

2.3.1 Prevalence of Exercise

With clear recommended minimum guidelines for exercise to confer a health benefit established, it might be expected that a high percentage of a population would undertake regular physical activity. As was pointed out in *Chapter One*, this is not the case: less than 50% of adult Australians are undertaking 30 minutes of moderate intensity physical activity on all or at least 5 days of the week (Armstrong, Bauman & Davies 2000; Australian Institute of Health and Welfare 2003). Given the recognised benefits of exercise, these data are alarming. The Australian data are reflected in global trends (World Health Organization 2003a), (Table 6).

Table 6: Prevalence of Physical Activity

Physical Activity Category	Australian Prevalence: Percentage Active		World Prevalence: Percentage Active
	Year		Year
	1999 (Armstrong, Bauman & Davies 2000)	2000 (Australian Institute of Health and Welfare 2003)	2002 (World Health Organization 2003a)
Sufficiently active	57%	43.6%	42%
Some but not sufficiently active	29%	40.3%	41%
Sedentary	14.6%	16.1%	17%

The prevalence of physical activity does not correspond with the guidelines and individual knowledge about the benefits of exercise. The Australian data indicated that while respondents' knowledge increased between 1997 and 1999, physical activity levels declined (Armstrong, Bauman & Davies 2000), a result supported by Scottish researchers (Crombie et al. 2004). Indeed, conclusions from a randomised

controlled trial, were that increasing knowledge by giving exercise advice to 1,658 middle-aged men and women registered at two medical centres was no more effective at increasing activity than no advice at all (Hillsdon et al. 2002). This has implications for the CDSMP, which does not include supervised exercise but which includes discussions about the benefits of exercise and gives guidelines on commencing an exercise regime. However, action planning provides opportunity to begin exercise.

2.4 Chronic Disease Self-Management Program and Exercise

As this is a review of published research concerning the CDSMP and exercise it includes randomised controlled trials and cohort studies. There were no case studies retrieved. The studies reported have measured quantitative outcomes. These measures yield useful information but, as explained in *Chapter Three* and in concurrence with others (Wright et al. 2003), they cannot be expected to tell us about the behaviour change people may undertake, barriers and enabling factors to such change and what is important to them with respect to healthcare interactions. These data are typically found in qualitative research, which is reviewed and reported later in this section.

2.4.1 Quantitative Studies

2.4.1.1 Studies Measuring Exercise as an Outcome

When considering the outcomes of the CDSMP studies, an additional caution is sounded by others with respect to lack of a stipulated primary outcome and that changes observed in the CDSMP trials referred to in Table 7 are small (Taylor & Bury 2007). A recent broadcast referred to the 'small effect sizes' following the CDSMP in the United Kingdom (Swan 2007). These observations are supported by a recently published Cochrane Review that found changes may be statistically significant, but the improvement was small (Foster et al. 2007). However, for people like those with COPD who may be much compromised in their abilities, a small effect may represent a meaningful improvement to the participant. Changes that are meaningful to the participants have not been determined for the self-reported exercise measure used in the CDSMP studies. Therefore it is difficult to judge the effectiveness of the programme by statistical significance or effect sizes alone.

Table 7: CDSMP Studies and Exercise

Author(s) Year	Study Type, Follow-up, Sample size	Country, Ethnicity, Gender, Age (years)	Exercise: Aerobic, Stretching and Strengthening (* significant increase; ** significant decrease)
Elzen et al. (2007)	RCT. Baseline, completion, 6 months <i>Recruited:</i> Intervention 70; Control 74 <i>Analysed:</i> Intervention 68 on completion, 67 at 6 months Control 68 on completion, 62 at 6 months	Netherlands Ethnicity not reported <i>Females:</i> Intervention 63.2%; Control 63.2% <i>Age:</i> Intervention 68.2; Control 68.5 <i>Conditions:</i> cardiac, respiratory, arthritis, diabetes	No significant differences between groups for aerobic exercise Stretching and strengthening exercise not included Change within group not reported
Kennedy et al. (2007)	RCT. Baseline and 6 months <i>Recruited:</i> 629 <i>Analysed:</i> Intervention 248; Control 273	United Kingdom <i>Caucasian:</i> Intervention 95%; Control 95% <i>Female:</i> Intervention 55%; Control 55% <i>Age:</i> Intervention 55.5; Control 55.3 <i>Conditions:</i> chronic disease, not specified	*Increased ($p = 0.047$) Reported as total exercise
Siu et al. (2007)	RCT. Baseline and one week post CDSMP <i>Recruited:</i> 160 <i>Analysed:</i> Intervention 76; Control 72	China, Hong Kong <i>Chinese</i> <i>Female:</i> 75% of total group <i>Age:</i> Not reported for the whole group, other than 58% were aged 45-55 years. <i>Conditions:</i> chronic disease, not specified	*Increased ($p = 0.000$), but no difference compared with control group who attended Tai Chi Reported as total exercise

Note: RCT = randomised controlled trial

Table 7 (continued)

Author(s) Year	Study Type, Follow-up, Sample size	Country, Ethnicity, Gender, Age (years)	Exercise: Aerobic, Stretching and Strengthening (* significant increase; ** significant decrease)
Bell and Orpin (2006)	Cohort Study. Baseline, 6, 12, 24 months <i>Recruited:</i> 264. 204 enrolled in CDSMP <i>Analysed:</i> 148, including those not participating in a programme	Australia <i>Caucasian:</i> 92.4% <i>Female:</i> 81% enrolled in CDSMP <i>Age:</i> 62 -72 <i>Conditions:</i> cardiac, respiratory, arthritis, diabetes, depression, renal, osteoporosis	**Decreased from baseline to 6 months ($p = 0.043$) Reported as total exercise
Swerissen et al. (2006)	RCT. Baseline, 6 months <i>Recruited:</i> 728 <i>Analysed:</i> Intervention 320; Control 154	Australia <i>Culturally and linguistically diverse population</i> <i>Female:</i> Intervention 73%; Control 79% <i>Age:</i> Intervention 66.4; Control 65.4 <i>Conditions:</i> cardiac, respiratory, arthritis, hypertension	*Increased ($p = 0.005$) Reported as total exercise
Griffiths et al. (2005)	RCT. Baseline, 4 months <i>Recruited:</i> 476 <i>Analysed:</i> Intervention 221; Control 21	United Kingdom <i>Bangladeshi</i> <i>Female:</i> Intervention 56%; Control 58% <i>Age:</i> Intervention 48.9; Control 48.0 <i>Conditions:</i> cardiovascular, respiratory, arthritis, diabetes	Not measured
Haas et al. (2005)	RCT. Baseline, 6 months <i>Recruited:</i> Intervention 60; Control 60 <i>Analysed:</i> Intervention 54; Control 47	USA. Caucasian, African- American <i>Caucasian:</i> Intervention 82%; Control 90% <i>Female:</i> Intervention 82%; Control 88% <i>Age:</i> Intervention 78.6; Control 75.5 <i>Conditions:</i> low back pain	Not measured

Note: RCT = randomised controlled trial

Table 7 (continued)

Author(s) Year	Study Type, Follow-up, Sample size	Country, Ethnicity, Gender, Age (years)	Exercise: Aerobic, Stretching and Strengthening (* significant increase; ** significant decrease)
Lorig et al. (2005)	RCT. Baseline, 4, 12 months <i>Recruited:</i> CDSMP: 116; ASMP: 239 <i>Analysed:</i> CDSMP: 104 at 4 months, 97 at 12 months ASMP: 220 at 4 months, 209 at 12 months	USA <i>Caucasian</i> CDSMP: 92.4%; ASMP: 86.9% <i>Female:</i> CDSMP:77.8%; ASMP: 81.3% <i>Age:</i> CDSMP: 77.8; ASMP: 81.3 <i>Conditions:</i> arthritis	CDSMP Increased aerobic, not significant at 4 months ($p = 0.09$), decreased at 12 months, not significant ($p = 0.766$) *Increased stretching and strengthening at 4 months ($p = 0.017$), and 12 months, but not significant (p $= 0.314$) Arthritis self-management programme (ASMP) Increased aerobic at 4 months ($p =$ 0.001) and 12 months but not significant ($p = 0.066$) Increased stretching and strengthening at 4 months ($p < 0.001$) and 12 months ($p < 0.001$)
Farrell et al. (2004)	Cohort Study. Baseline, completion of the CDSMP <i>Recruited and analysed:</i> 48	USA. <i>Caucasian:</i> 79.2%, <i>African- American:</i> 20.8% Low income, urban population. <i>Female:</i> 81% <i>Age:</i> 59.7 <i>Conditions:</i> cardiac, respiratory, arthritis, diabetes, depression, hypertension, cancer, chronic pain, hyperlipidaemia	Increased walking time but not significant ($p = 0.42$) No median change stretching and strengthening
Murphy et al. (2004)	RCT. Baseline, completion of programmes, 6 months <i>Recruited:</i> CDSMP 19; PRP alone 53; PRP exercise not reported <i>Analysed:</i> CDSMP: 18 on completion, 11 at 6 months PRP alone: 42 on completion, 23 at 6 months PRP exercise: 16 on completion, 11 at 6 months	Australia <i>Ethnicity</i> not reported <i>Female:</i> 46.8% total sample <i>Age:</i> 69 total sample <i>Conditions:</i> respiratory	Increased distance walked on incremental shuttle walk test Compared CDSMP with traditional pulmonary rehabilitation programme (PRP) alone or PRP with weekly maintenance exercise

Note: RCT = randomised controlled trial

Table 7 (continued)

Author(s) Year	Study Type, Follow-up, Sample size	Country, Ethnicity, Gender, Age (years)	Exercise: Aerobic, Stretching and Strengthening (* significant increase; ** significant decrease)
Fu et al. (2003)	RCT. Baseline, 6 months <i>Recruited:</i> 954 <i>Analysed:</i> Intervention 430; Control 349	China, Shanghai <i>Han:</i> Intervention 96%; Control 98% <i>Female:</i> Intervention 73%; Control 69% <i>Age:</i> Intervention 64; Control 64 <i>Conditions:</i> cardiovascular, respiratory, arthritis, diabetes, hypertension	*Increased ($p = 0.01$) Stretching and strengthening exercise adapted to Chinese culture. Reported as total exercise
Lorig et al. (2003)	RCT. Baseline, 4 months <i>Recruited:</i> 551 <i>Analysed:</i> Intervention 265 Control 178	USA. <i>Hispanic.</i> CDSMP offered in Spanish. <i>Female:</i> Intervention 80%; Control 79% <i>Age:</i> Intervention 56.6; Control 56.1 <i>Conditions:</i> cardiac, respiratory, diabetes	*Increased ($p = 0.001$) Reported as total exercise
Wright et al. (2003)	Cohort Study. Baseline, 4 months <i>Recruited:</i> 232 <i>Analysed:</i> 185	United Kingdom. <i>Caucasian:</i> 97% <i>Female:</i> 72% <i>Age:</i> 53 <i>Conditions:</i> endometriosis, depression, diabetes, myalgic encephalomyelitis, polio, osteoporosis	Decrease aerobic, not significant ($p = 0.848$) No significant change stretching and strengthening
Lorig et al. (2001b)	Cohort Study. Baseline, 12 months <i>Recruited:</i> 613 <i>Analysed:</i> 489	USA. <i>Caucasian:</i> 83% <i>Female:</i> 73% <i>Age:</i> 62.2 <i>Conditions:</i> cardiac, respiratory, arthritis, diabetes	*Increased aerobic ($p = 0.01$) *Increased stretching and strengthening ($p \leq 0.001$)

Note: RCT = randomised controlled trial

Table 7 (continued)

Author(s) Year	Study Type, Follow-up, Sample size	Country, Ethnicity, Gender, Age (years)	Exercise: Aerobic, Stretching and Strengthening (* significant increase; ** significant decrease)
Lorig et al. (2001a)	Longitudinal follow-up to above RCT (1999) <i>Recruited:</i> 831 <i>Analysed:</i> 683 at 12 months, 533 at 24 months	USA. <i>Caucasian:</i> 90.8% / 91.2% (at 12 / 24 months) <i>Female:</i> 65.4% at 12 months; 68.5% at 24 months <i>Age:</i> 65.3 at 12 months; 64.8 at 24 months <i>Conditions:</i> cardiac, respiratory, cerebrovascular, arthritis	Not measured
Lorig et al. (1999)	RCT. Baseline, 6 months <i>Recruited</i> 1140 <i>Analysed:</i> Intervention 561; Control 391	USA <i>Caucasian:</i> Intervention 91%; Control 89% <i>Female:</i> Intervention 65%; Control 64% <i>Age:</i> Intervention 65.6; Control 65 <i>Conditions:</i> cardiac, respiratory, cerebrovascular, arthritis	*Increased aerobic (p = 0.005) *Increased stretching and strengthening (p = 0.0003)

Note: RCT = randomised controlled trial

Outcomes in the studies listed in Table 7 were measured by self-report of minutes spent engaging in exercise according to the questions developed by the Stanford Patient Education Centre (Lorig et al. 1996). Although this measure differentiates between ‘aerobic’ exercise and ‘stretching and strengthening’ exercises, some studies reported this as total exercise (Bell & Orpin 2006; Fu et al. 2003; Kennedy et al. 2007; Lorig, Ritter & Gonzalez 2003; Siu et al. 2007; Swerissen et al. 2006), others adapted the measure to reflect cultural exercises (Fu et al. 2003) or did not include the question pertaining to stretching and strengthening exercise (Elzen et al. 2007). Three of 14 studies did not measure exercise and no reason was given (Griffiths et al. 2005; Haas et al. 2005; Lorig, Ritter et al. 2001).

As the outcome was by self-report, with the exception of one study (Murphy et al. 2004), no objective measures were used to determine physical capacity. Murphy et al. (2004) provided a quantitative measure of physical capacity using the incremental

shuttle walking test. Additionally, no study ascertained if minimum recommended levels of daily exercise were being attained.

2.4.1.2 Time Course

While recognising the sustainability of outcomes needs to be evaluated, it is curious that only three studies performed an immediate post-programme evaluation (Elzen et al. 2007; Farrell, Wicks & Martin 2004; Siu et al. 2007). By measuring a post programme effect, any change is then able to be immediately monitored. It could then be determined if exercise behaviour is influenced by a brief six-week intervention or if there is a delay in adopting exercises. Siu et al. (2007) suggest immediate post CDSMP measurements could serve as a baseline for measuring sustainability of any change.

2.4.1.3 Gender

With the exception of two studies in the United Kingdom (Griffiths et al. 2005; Kennedy et al. 2007), female participants accounted for over 63% of those recruited to the studies, an observation recently supported by others with respect to Australian programmes (Nolte et al. 2007). This must be borne in mind when interpreting the exercise data and prior to attributing levels of participation to gender influences. It is noted that a survey of exercise levels of older Australians revealed more men (55%) than women (38%) undertook sufficient exercise (Booth et al. 2000).

2.4.1.4 Age

The average age range of participants in the studies reported in Table 7 was from middle age (45 years) to older adults (77.8 years). Age has been implicated in the adoption of exercise, with an increased likelihood of sedentary behaviour with increasing age (Mullineaux, Barnes & Barnes 2001). However, in 449 older Australians (aged 60 years or more) the group reporting the most exercise activity was 65–69 years (Booth et al. 2000), an age group represented by some of the CDSMP studies reporting significant increases in self-reported exercise (Lorig, Sobel et al. 1999; Murphy et al. 2004; Swerissen et al. 2006). As Booth et al. (2000) suggest, perhaps the higher levels of exercise in the 65–69-year-old group reflects the retirement age of 65 years in Australia, and the influence of having more time to exercise. Nevertheless, it is encouraging that self-reported exercise levels increased

following the CDSMP, especially in the older age groups (60–77.8 years) as many older Australians cite poor health as a barrier to exercise (Booth et al. 1997).

2.4.1.5 Socioeconomic Status

Other demographic factors such as lower socioeconomic status and lower education have been cited as barriers to exercise for American adults aged 19 years and over (Stutts 2002) and for English adults aged 16 years or older (Mullineaux, Barnes & Barnes 2001). These observations are supported by population studies in Australia (Armstrong, Bauman & Davies 2000). It is therefore of note that the participants from ethnic backgrounds in an Australian study had less than eight years of education (intervention group: 7.08 years, control group 6.21 years), yet showed a significant increases in minutes per week spent exercising (Swerissen et al. 2006), implying that education was not be a barrier for the people in the study.

2.4.1.6 Impact

Reference to Table 7 shows that for exercise measured at either four or six months post CDSMP, two studies reported a significant increase in self-reported aerobic exercise and stretching/strengthening exercises (Lorig, Sobel et al. 2001; Lorig, Sobel et al. 1999) and one study in stretching and strengthening exercises only (Lorig, Ritter & Plant 2005). An additional five studies found an increase in total exercise (Fu et al. 2003; Kennedy et al. 2007; Lorig, Ritter & Gonzalez 2003; Siu et al. 2007; Swerissen et al. 2006). Thus 66% ($\frac{8}{12}$) of the studies in which exercise behaviour was measured reported a significant increase in some aspect of exercise behaviour following the CDSMP compared to controls.

In contrast, three of the studies reported no significant increase in any form of self-reported exercise (Elzen et al. 2007; Farrell, Wicks & Martin 2004; Wright et al. 2003). The authors acknowledge that these cohort studies limit the strength of the evidence which Wright et al. (2003) describe as exploratory in nature. The authors also suggest the outcome measure may not be sensitive enough to detect small changes in exercise behaviour that may be meaningful to the individual. Finally, high levels of health behaviours at baseline was suggested as a possible reason for no observed change (Elzen et al. 2007) and exercise was not discussed as a separate outcome in the study by Lorig and colleagues (2005).

Only one study reported a significant decrease in exercise (Bell & Orpin 2006). The authors note that the cohort included people who had not participated in any intervention, as well as those who attended the CDSMP. It is impossible to definitively conclude that the decline is an effect of the CDSMP as there are potential confounders.

2.4.1.7 Barriers

When interpreting exercise data and considering interventions to facilitate exercise adoption, other barriers such as environmental safety, reluctance to meet new people (Crombie et al. 2004) and lack of time (Stutts 2002) need to be considered. Additionally, Booth et al. (1997) found that older people did not find group-based exercise attractive, preferring to seek advice and implement an exercise regime independently. The CDSMP allows for this preference. As explained previously in *Chapter One*, the CDSMP does not have supervised group exercise, yet does offer advice about implementing an exercise regime of choice, and in a time frame chosen by the individual. Based on Booth et al.'s (1997) research, the CDSMP structure may facilitate the adoption of exercise for older Australians. The study for this thesis is therefore timely, as population health approaches endeavour to encourage the adoption of exercise for an 'Active Australia' (Australian Government Department of Health and Aging 2005), including those with chronic conditions such as COPD.

Intervention programmes such as the CDSMP have the potential to target individual factors posing barriers to exercise. These include lack of interest, lack of belief in the benefits of physical activity and lack of motivation (Crombie et al. 2004; Mullineaux, Barnes & Barnes 2001; Stutts 2002). Low self-efficacy (akin to confidence) is associated with low levels of participation, thus representing a potential barrier to activity adoption (Stutts 2002). Self-efficacy and its role in exercise behaviour adoption or maintenance was pointed to in the preceding chapter. Exercise self-efficacy studies in the COPD literature are noted later in this chapter.

2.4.2 Qualitative Studies

Qualitative research into the experience of exercise following the CDSMP is limited. However, qualitative research concerning the general participant experience of the CDSMP has provided some insight into what participants valued in this programme.

Therefore, this research was considered, as it could yield insights for this thesis. The reported studies and findings are depicted in Table 8.

Table 8: Qualitative CDSMP Studies

Author(s), year	Data collection, Sample, Aim	Demographics	Findings
Siu et al. (2007)	Log books <i>Sample size:</i> Given to all enrollees in the study (n= 160). Number in analysis not given <i>Aim:</i> record, monitor goals; action plans	China, Hong Kong <i>Chinese</i> Details of those whose log books were analysed are not given.	<i>Analysis of goals, action plans, progress:</i> not reported <i>Suggestions for improvement:</i> Review sections related to death and dying and to communication with health professionals
Fu et al. (2006)	Interviews <i>Sample size:</i> 57 purposeful sample <i>Aim:</i> explore participant perception of CDSMP on health and determine cultural acceptability	China <i>Ethnicity:</i> Han % not reported <i>Female:</i> 75.4% <i>Age:</i> 63 <i>Education:</i> not reported	<i>Benefits:</i> Increased knowledge of health behaviours and self-management Developing new self-management skills: setting action plans, emotional control, communication Changing health behaviours Increased confidence <i>Disliked:</i> Feedback and problem-solving each week <i>Mechanism of CDSMP effect:</i> Behaviour change, emotional control, self-efficacy <i>Culturally acceptable</i>
Rose et al. (2006)	Focus groups (4) <i>Sample size:</i> 25 <i>Aim:</i> implied seeking an understanding of programme benefits and difficulties	USA <i>Ethnicity:</i> African-American <i>Females:</i> <i>Age:</i> 'elders' <i>Education:</i> not reported. Low income, urban	<i>Benefits:</i> Group participation <i>Difficulties:</i> Setting action plans <i>Suggestions for improvement:</i> Follow-up sessions addressing problem-specific information
McGowan (2003)	Interviews <i>Sample size:</i> 26 randomly selected <i>Aim:</i> implied seeking an understanding of programme benefits	Canada <i>Ethnicity:</i> not reported <i>Females:</i> 20/26 (76.9%) <i>Age:</i> 59 <i>Education:</i> 14	<i>Benefits:</i> Learning to self-manage, to set action plans, to be more aware of self and others Developing new skills Changing health behaviours

Only two journal publications reporting qualitative findings were located (Fu et al. 2006; Siu et al. 2007), one conference presentation (Rose et al. 2006) and three reports (McGowan 2000, 2001, 2003). Two of the reports give little participant data, presented descriptive data only and do not attempt any analysis (McGowan 2000, 2001). Therefore, they are not included in the following discussion. However, the authors comment that the findings presented in the third report support those of the preceding studies.

The qualitative research reported in the CDSMP-related literature to date has been largely limited to data pertaining to the benefits and difficulties experienced during the CDSMP. However, as a first step towards understanding the participant experience, it is important to appreciate what people liked and disliked about the programme.

Setting action plans, changing health behaviours and increased self-management were cited as benefits in two studies (Fu et al. 2006; McGowan 2006). In contrast, Rose et al. (2006) reported older participants from a low-income area overwhelmingly endorsed the CDSMP, yet found action planning, a cornerstone of this programme, difficult to implement. Chinese participants, who found the programme to be culturally acceptable, disliked weekly feedback and problem-solving, key components of the CDSMP (Fu et al. 2006). Unfortunately, while Sui et al. (2007) stated the data from log books from a Chinese sample would be analysed in a context of behavioural change, they did not report on this.

Fu et al. (2006) take the analysis a step further in suggesting a mechanism through which the CDSMP effects are mediated. However, they do not explore this further in terms of invoking theories of behaviour change, other than to state that self-efficacy appeared to be a causal agent. These authors reported a number of changed health behaviours. Some of these changes — such as medication usage, changing eating habits and ceasing smoking — were not captured by the quantitative measures, leading the authors to conclude that the measures may need revising. This study suggests that while preselected quantitative measures provide information about health indicators and health status, they cannot tell us, as qualitative methods are situated to do, what is important from the participant's perspective.

The findings endorsing self-management are not surprising when it is considered that the move towards individuals being involved in determining their own healthcare is not new, beginning in the latter part of the 20th century (Eweles & Simnett 2003). Over thirty years ago the literature indicated that patients wanted to be active informed participants in their own healthcare (Haug & Lavin 1979; Vertinsky, Thompson & Uyeno 1974). The book, *Through the Patient's Eyes* was an early reference to patient-centred care (Gerteis 1993). Others have also reported the shift from a model driven by the health professional's perspective to one that is inclusive of the patient's viewpoint (Bauman 2003; Davis, Schoenbaum & Audet 2005; Laine & Davidoff 1996). This collaborative approach will be explored further in this thesis.

It is of interest that nine participants in the study by Fu et al. (2006) had COPD. Managing their health through physical exercises was reported by 61.2% (36) of the people interviewed in their study, but the authors did not discuss this further. Qualitative methods of enquiry are well situated to provide a window through which the mechanisms, facilitators and barriers of behaviour change may be glimpsed as seen through the participants' eyes. Qualitative enquiry provides a human dimension to quantitative measures such as exercise self-efficacy, one proposed mechanism of health-behaviour change such as the adoption of exercise, which was discussed in *Chapter One*. Exercise and self-efficacy with relation to COPD are discussed further below.

2.5 *Exercise Self-efficacy and COPD*

Social cognitive theory would suggest that if exercise self-efficacy is to be facilitated, then people with COPD would need to practise and master the exercise behaviour. The studies reported below support this proposal.

Statistically significant increases in self-reported minutes per week spent walking and in walking self-efficacy have been observed following interventions based on cognitive, behavioural and cognitive-behavioural modification versus attention-controls and a group receiving no treatment (Atkins et al. 1984). The three groups receiving intervention based on psychological theory had greater exercise tolerance than the two other groups and this was evident at three months post intervention. Others have compared comprehensive cardiopulmonary rehabilitation (supervised

exercise, psychosocial support and education) with education alone (Toshima, Kaplan & Ries 1990). While the authors note a positive correlation between self-efficacy for walking and exercise endurance six months post rehabilitation but not for education alone, they did not report any details.

More recently, a significant positive correlation was observed in a convenience sample of 48 participants with COPD between self-efficacy for walking and performance on a treadmill exercise test (Jeng et al. 2002). Others found a positive correlation between daily physical activity measured by an accelerometer and the distance walked in the 6-minute walk test (6MWT) ($r = 0.60$, $p < .00$) and with walking self-efficacy ($r = 0.27$, $p < 0.05$) in a convenience sample of 63 people with COPD (Belza et al. 2001). These results could be explained by social cognitive theory. As a person develops mastery for the task (increased walking, despite having COPD), their belief in their ability to achieve the goal of increased walking (walking self-efficacy) would be enhanced. Explained differently, those who have higher daily activity levels and higher physical capacity, as measured by the 6MWT, would be expected to have higher self-efficacy for this behaviour.

These outcomes raise the question as to whether or not an approach grounded in behaviour-change theory, such as the CDSMP, would be more effective for exercise adoption than one where such a deliberate focus has not been articulated. One randomised controlled trial (Murphy et al. 2004) begins to answer this query, in that no statistically significant difference was observed between distances walked in the incremental shuttle walk test for people attending either the CDSMP or traditional cardiopulmonary rehabilitation immediately post-programme or at six months follow-up (Table 7). The effect of supervised exercise added to the CDSMP was not investigated.

It must be noted that traditional cardiopulmonary rehabilitation programmes also aim to encourage exercise adoption. The question of how this traditional approach fits with chronic disease self-management interventions and the CDSMP in particular will be addressed in the following section.

2.6 *Chronic Disease Self-Management Interventions*

To manage the often variable impact of a condition such as COPD, people require resources, in terms of personal skills, medical care and social assistance (Thorne, Nyhlin & Paterson 2000). If they are to adopt new health behaviours they should be given personal feedback about their health and then given the support they require to assist such change (McMurray 2002). This support is referred to as self-management support (Bodenheimer et al. 2002). Chronic disease self-management (CDSM) interventions are one vehicle for addressing and providing support for behaviour change (Wagner, Austin & Von Korff 1996). Approaches to self-management interventions are considered below.

2.6.1 Chronic Disease Self-Management Reviews

A number of reviews addressing CDSM have been published in the last five years (Barlow et al. 2002; Bury, Newbould & Taylor 2005; Chodosh et al. 2005; Foster et al. 2007; Newman, Steed & Mulligan 2004; Warsi et al. 2004; Weingarten et al. 2002). Definitions of CDSM as an intervention varied amongst reviewers. Some defined CDSM interventions as patient education including self-monitoring of the condition and decision-making (Chodosh et al. 2005), while others suggested that CDSM should include education of both patient and provider (Weingarten et al. 2002). Only one review referred to the interventions being situated in a participant-centred context (Foster et al. 2007).

While some limited their reviews to a combination of prevalent conditions such as hypertension, osteoarthritis, diabetes or asthma (Chodosh et al. 2005; Newman, Steed & Mulligan 2004), additional chronic conditions were included in other reviews (Barlow et al. 2002; Foster et al. 2007; Warsi et al. 2004; Weingarten et al. 2002). The majority of studies evaluated condition-specific education for patients, with various modes of delivery, ranging from group-based to individual. The CDSMP was noted as a generic model (Barlow et al. 2002; Newman, Steed & Mulligan 2004) and was included in a recently published systematic review of lay-led self-management interventions (Foster et al. 2007).

Examples of different modes of delivery of CDSM include the group-based approaches such as the CDSMP (Lorig, Ritter et al. 2001), group visits with

physicians (Wellington 2001), the Health Partners Programme — which incorporates CDSMPs, physician group visits, and email discussion groups between patients and their physicians (Shoor & Lorig 2002). Individual interventions include telephone follow-up (Wasson, Gaudette & Whaley 1992), the generic Flinders CDSM model (Battersby et al. 2003), and individual mentoring approaches such as the Good Life Club for people with diabetes (Kelly, Menzies & Taylor 2003), the COACH programme for those with cardiovascular disease (Vale et al. 2003) or mentoring used with alcohol and other drug services (McDonald 2002). Recently, there have been reports of the use of information technology to assist people in monitoring and managing their chronic conditions, including COPD (Lorig et al. 2006; Nguyen et al. 2005).

Reviewers noted that the array of interventions and outcome measures rendered comparison difficult and the different definitions of CDSM make comparison of reviews difficult. However, in support of Wagner et al. (Wagner, Austin & Von Korff 1996), it appears that regardless of the mode of delivery, self-management interventions appear to benefit individuals in terms of improved knowledge, self-management behaviours, self-efficacy, health status (Barlow et al. 2002), disease control (Weingarten et al. 2002) and in some physiological measures (Chodosh et al. 2005). It also improves provider adherence to guidelines (Weingarten et al. 2002). How these compare with traditional approaches is difficult to ascertain because there is scant reference to comparative studies in the literature.

Foster et al. (2007), in support of Bury's observation (2005), noted the improvements following self-management interventions to be small and, as outcomes were not measured beyond six months, sustainability is unclear. Of relevance to this thesis is the small statistically significant increase in self-reported aerobic exercise reported in seven of 17 studies following the CDSMP, arthritis and other lay-led self-management interventions reviewed by Foster et al. (2007). The authors reported a standard mean difference of -0.20 and 95% confidence interval of -0.27 to -0.12. They note the lack of effect on clinical measures such as the 6MWT.

As well as differing in modes of delivery, CDSM approaches differ from traditional approaches with respect to their objectives and content. The objectives and hence content of many more traditional programmes are orientated to managing the

symptoms of the condition (Newman, Steed & Mulligan 2004). This is particularly so in the COPD-related literature, which will be discussed in the following section.

2.6.2 Chronic Disease Self-Management and COPD

One of the earliest references to self-management and COPD is related to managing shortness of breath (Zimmerman, Brown & Bowman 1996). Since then other studies have also focused on managing symptoms. Following a symptom-related action plan is referred to as self-management in much of the COPD-related literature (Gallefoss 2004; Gallefoss & Bakke 1999, 2000; Watson et al. 1997; Wood-Baker et al. 2006; Worth 1997). This concept was evident in a review of 'Self-management Education' (Monninkhof et al. 2003a), which was defined as combining an education intervention to increase knowledge and understanding of COPD with 'self-treatment', that is, following a symptom action plan. While studies including exercise were not excluded per se, those evaluating the effects of pulmonary rehabilitation of which exercise is a component were. The authors did not define pulmonary rehabilitation. The reviewers concluded that, due to the variety of outcome measures used, the evidence for their definition of self-management education was inconclusive (Monninkhof et al. 2003a).

It must be noted that following a symptom-related action plan is only one of the acknowledged self-management activities described previously. To focus only on this risks losing sight of holistic care. However, monitoring the condition, interpreting any change, and acting in accordance with guidelines, that is, following a symptom-related action plan, fits with the concept of self-regulation of behaviour change (observation, judgment and reaction) referred to in the previous chapter (Clark; Gong & Kaciroti 2001; Schwarzer 2001). The authors referred to above did not articulate this concept.

Pulmonary rehabilitation is an intervention aiming to improve the health of people with COPD, by encouraging the adoption of health-related behaviours. It is not referred to as self-management, although there is a focus on people learning skills to improve life with COPD. Nevertheless, as the outcomes of cardiopulmonary rehabilitation attest, improvements in participants' functional capacity and health-related quality of life, suggestive of behaviour change, do result (Celli 1995; Lacasse et al. 2002; Lacasse et al. 2004; Lacasse et al. 2006; McKenzie, Frith & Burdon

2003). Whether or not these improvements would be augmented by an approach deliberately facilitating the development of self-management activities and enhancing self-efficacy is not reported.

The outcomes of the above reviews are interesting, as they raise the question as to which is more effective: an exercise focus (Lacasse et al. 2006) or a symptom-related action plan focus (Monninkhof et al. 2003a). A further review, drawing the studies together, is needed to begin to answer this question. Neither of these approaches with a singular focus can be termed 'self-management' in a holistic sense. Rather, the reviews are focusing on single self-management behaviours.

Recently, some authors have begun to address the theoretical basis of interventions. It has been suggested that rehabilitation programmes that included methods to facilitate self-efficacy for managing symptoms of COPD should be developed (Scherer, Schmieder & Shimmel 1998). Monninkhof et al. (2003) suggest that patients with COPD should be equipped with skills to enhance sustained behaviour change and facilitate self-efficacy development. However, they do not elaborate further. The COPDX Guidelines identify the development of coping skills and self-management behaviours as strategies for managing life with COPD. The guidelines see improved self-efficacy as an outcome of rehabilitation, but do not define the behavioural domain(s) for self-efficacy. They do not provide further detail, nor comment on the most desirable process(es) by which this might be achieved (Abramson et al. 2006; McKenzie, Frith & Burdon 2003).

Borbeau et al. (2004) describe how self-efficacy is enhanced in their comprehensive intervention but they did not measure self-efficacy for any specific behaviour. However, the authors note that an individual needs to be ready to change, providing one of the first acknowledgments of this concept in the literature pertaining to adopting health behaviours for people with COPD. They do not pursue this further (Borbeau et al. 2003; Bourbeau, Nault & Dang-Tan 2004).

Two of the above authors (Bourbeau 2003; Monninkhof 2003) have developed different self-management interventions for people with COPD. Monninkhof et al.'s (2003) study was group-based with nurse-delivered condition-specific education and group-based exercise, similar to traditional pulmonary rehabilitation. In contrast,

Bourbeau et al. (2003) devised individual education sessions with telephone follow-up and an at-home unsupervised exercise programme. Both these interventions differ to the process of delivery for the CDSMP, described in *Chapter One: Context of the Thesis*. With the exception of condition-specific symptom monitoring and management, similar topics to the CDSMP are included in Monninkhof et al.'s (2003) and Bourbeau et al.'s (2003) interventions. Similar to the CDSMP, a home exercise programme was the responsibility of participants in both studies. Guided feedback and problem-solving to address barriers to achieving participant-identified goals and action plans are not reported in the above two studies and are thus differentiating features compared with the CDSMP.

Both Monninkhof et al. (2003) and Bourbeau et al. (2003) found no statistically significant difference in walking distance measured at 12 months. Health-related quality of life measured by the St. George's Respiratory Questionnaire showed little improvement at 12 months in Bourbeau et al.'s (2003) study, and no positive change in Monninkhof et al.'s (2003) study. The latter observe that the above outcome measures may not reflect small changes that are important to participants.

The exercise component of the self-management studies referred to above covered general exercises (stretching, strengthening, cardiovascular). The efficacy of this general approach was compared with a programme targeting problematic individual daily activities (Sewell 2005). The investigators reported no significant difference between the general exercise programme and the approach directed to individual functional activities. This result is relevant to my thesis as it provides support for the exercise intervention used in my study. As it will be explained in the following chapter the exercise intervention was the general approach used in current clinical practice.

Make (1994, 2003) provides a more comprehensive approach to self-management for people with asthma and COPD in a review of clinical trials with a discussion of suggested strategies. He prefers to use the term 'collaborative self-management', to denote a partnership between patient and health care professional, with goals congruent between healthcare provider and patient. Make (2003) includes education, the patient's readiness and ability to assimilate knowledge, monitoring of the self-management process and family involvement in his approach to collaborative self-

management, thereby supporting the work of Clark et al. (1991). He also notes the importance of communication from the healthcare provider point of view but fails to mention this with respect to the person with the condition. Make's approach is suggestive of CDSM within a participant-centred framework, and is the first to allude to this in the COPD literature.

2.8 Chapter Summary

In summary, COPD is a progressive condition and with increasing severity it profoundly affects the lives of an increasing number of people who face losses and challenges as to how they perceive themselves and to the expectations they hold. Maintenance of the best possible health for people with COPD is one objective of healthcare interventions. Exercise is a modifiable health-related behaviour with demonstrated health benefits for people with COPD.

Increasingly governments and health professionals are recognising that an acute medical model of care is not appropriate for facilitating the development of skills for people to manage the impact of chronic conditions on their daily lives. Self-management skills enable people with long-term conditions to integrate health behaviours such as exercise into their daily lives.

To this end, alternative models focusing on chronic disease management and underpinned by health behaviour change theories are being explored and adopted. The Stanford CDSMP is one such approach. It does not incorporate supervised exercise, yet studies report an increase in self-reported exercise following attendance at the programme. Supervised exercise is strongly recommended by the COPD management guidelines.

Few studies have explored how participants experience the CDSMP and none with respect to exercise and the CDSMP. The qualitative studies indicate that the experience of the CDSMP is a positive one with self-efficacy suggested as a mechanism of change. No published studies addressing the addition of supervised exercise to the CDSMP with respect to quantifiable outcomes were retrieved. The quantitative studies reviewed suggest that the CDSMP facilitates exercise behaviour, despite the absence of supervised exercise.

This literature review has highlighted the need to investigate the addition of supervised exercise to the CDSMP, which purports to provide people with the tools to adopt health-related behaviours such as exercise as they refine or develop self-management skills. To further investigate this, a controlled clinical trial was planned using a mixed methods approach to quantitatively investigate the effect of supervised exercise with the CDSMP on physical capacity for people with COPD. Qualitative methods will illuminate that which is important to participants from a programme experiential viewpoint and, importantly, add to an understanding of the complexities of behaviour change.

3

CHAPTER THREE: METHODOLOGY

3.1 Introduction

The intent of this research was to inform clinical practice by investigating whether or not there would be a benefit to offering supervised exercise with the Chronic Disease Self-Management Program (CDSMP). The research sought objective evidence as well as identifying, through the participants' eyes, what was important to them with respect to this healthcare interaction, contributing to an explanation of their behaviour. This chapter details the research questions that arose from clinical practice and a review of the extant literature, the study design and the methodology employed to investigate these questions.

3.2 The Research Questions

Two overarching research questions guiding the quantitative and qualitative approaches to the inquiry arose:

1. For people with chronic obstructive pulmonary disease (COPD), what would be the effect of supervised exercise on physical capacity and exercise behaviour when offered with the CDSMP?

and

2. What is the lived experience of people with COPD who attend the CDSMP with or without supervised exercise?

Table 9: Research Questions and Outcome Measures

Primary Research Question	
<i>In people with COPD, what is the effect of supervised exercise with the CDSMP compared to the CDSMP without exercise on physical capacity?</i>	
Measure	
Physical capacity, measured by the distance walked in the 6-minute walk test (6MWT), a field walking test (Guyatt et al. 1985)	
Secondary Research Questions	
<i>What is the effect of supervised exercise with the CDSMP compared to the CDSMP without exercise on:</i>	
Measure	
<i>Self-reported exercise?</i>	Self-reported exercise was measured with the CHAMPS Physical Activity Questionnaire (Stewart et al. 2001)
<i>Self-efficacy for exercise?</i>	Self-efficacy for exercise was measured with the ‘Exercise: Self-Efficacy’ scale (Cancer Prevention Research Center 1991a)
<i>Exercise participation (achieving minimum recommended levels of daily exercise)?</i>	<p>The criteria to be met were explained, and participation measured by a dichotomous question :</p> <p>‘Regular Exercise is any planned physical activity (e.g., brisk walking, aerobics, bicycling, swimming, line-dancing, tennis, doing formal exercises etc.) performed to increase or maintain health and physical fitness. Such exercise should be performed on all or at least 5 days of the week to accumulate 30 minutes or more per day. Exercise does not have to be painful to be effective but should be done at a moderate level that increases your breathing rate and makes you feel warmer.</p> <p>Do you exercise regularly according to the definition above? Y/N</p>
<i>Stage of change for exercise?</i>	Stage of change for exercise was measured with the ‘Exercise: Stages of Change—Short Form’ questionnaire (Cancer Prevention Research Center 1991b).
<i>Shortness of breath (SOB)?</i>	SOB was measured with a Visual Analogue Scale (VAS) (American Thoracic Society 1999; Gift 1989; Nici et al. 2007)
<i>Self-management behaviours?</i>	Self-management behaviours were measured with the Flinders University Partners in Health (PIH) Scale (Battersby et al. 2003)
<i>Health-related quality of life (HRQoL)?</i>	HRQoL was measured with the Short Form- 36 version 2 Generic Health Survey (SF-36v2) (Ware, Kosinski & Dewey 2000).
Additional Questions	
<i>What are the predictors for the change, if any, in distance walked in the 6MWT?</i>	
<i>What are the differences, if any, between those interviewed and not interviewed?</i>	

The governing research questions were distilled into primary and secondary questions addressing quantitatively measured outcomes presented in Table 9.

To understand the lived experience of the CDSMP with or without supervised exercise some understanding of the impact of COPD on the lives of the participants,

the meaning of self-management to them and their reasons for enrolling in and continuing the study was necessary. The questions guiding the qualitative enquiry are presented in Table 10.

Table 10: Qualitative Research Questions

Data was collected by semi-structured interviews addressing the following questions:
<ul style="list-style-type: none">• How do people with COPD describe the impact of living with this condition?• Why did participants enrol in the programme?• Why did participants continue to attend?• Why did participants drop out?• What does self-management mean to participants with COPD?• What do people with COPD tell us about supervised exercise?• What do people with COPD tell us is important to them with respect to the CDSMP?• How has the CDSMP with or without supervised exercise influenced participants' experiences of living with a chronic condition?

To investigate these questions, the study was designed using mixed methods of quantitative and qualitative enquiry to provide triangulation. The rationale for the research and study design is explained below.

3.3 *Research Design: Triangulation using Mixed Methods*

A mixed methods approach was used in this study to provide triangulation. Triangulation refers to a combination of different approaches within the same study: sampling, methods or analyses (Hansen 2006). The primary aim of using this approach was to provide a more detailed analysis of the CDSMP with or without supervised exercise (CDSMP±Ex) than that obtained from one method alone (Brannen 1992; Hansen 2006). It was envisaged that this research would provide objective evidence to inform clinical practice that would be enriched by the lived experiences of the participants, rather than seeking convergence of data or supporting a theory.

Thus the research methodology was approached from two different theoretical paradigms: a quantitative objectivist paradigm and a qualitative inductive paradigm, which complemented each other. Within the quantitative paradigm, the use of a range of outcome measures (Table 9) provided objective measures of the effect of supervised exercise with the CDSMP.

The qualitative research aimed to provide insight into what being involved in the CDSMP or supervised exercise meant for participants and how they experienced living with COPD. Triangulation was provided by asking similar questions of different cohorts within the sample: the intervention group, controls, those who had attended other programmes previously and one person who withdrew. Such qualitative research is important: by understanding the experience of interventions such as the CDSMP and supervised exercise from the participants' viewpoint, health practitioners may be better able to develop healthcare services based not only on theory, but also on elements valued by those who participate.

The rationale for the quantitative and qualitative approaches is explained below.

3.3.1 Quantitative Study Design Rationale

An approach was sought that would enable the evidence base for the CDSMP to be supplemented in a rigorous manner with the strongest level of evidence possible. Double-blind randomised controlled trials are acknowledged as a study design aimed at minimising bias for a clinical intervention (National Health and Medical Research Council/Australian Vice-chancellors' Committee 2007). Randomisation contributes to protecting a study against allocation bias (Kunz, Vist & Oxman 2005; Schultz et al. 1995). However, in this study a double-blind trial was not possible as participants know who is attending a supervised exercise programme. In addition, the person supervising the questionnaires was also one of the people facilitating the CDSMP. This was unavoidable due to workplace constraints. Measures taken to counteract this potential source of investigator bias (Schulz & Grimes 2002) are described in the following section, 'Study Steps'.

A randomised controlled parallel clinical trial was planned in a clinical setting, as part of usual clinical practice. Participants attended supervised exercise or the CDSMP at the times they would usually operate, to maximise generalisability of results to the usual practice within the hospital.

3.3.2 Qualitative Study Design Rationale

The qualitative arm of the study was seen as enabling participants to state what they perceived to be the essence of supervised exercise and the CDSMP. While randomised controlled trials provide a strong evidence base for an intervention, such

trials do have their limitations (Dixon-Woods et al. 2005). To focus only on the quantitative outcomes of a randomised controlled clinical study such as the CDSMP with or without supervised exercise, is to endanger health professionals of choosing to accept only objective data as a measure of efficacy and so reject that which participants tell us is of importance to them (Bleakley 2005).

By listening to the voices of participants, gathering and analysing the stories they tell, we gain insight into what participants value and they in turn feel valued (Bleakley 2005; Riley & Hawe 2005). With a holistic focus we are able to gain an understanding what is meaningful to participants with respect to the CDSMP and supervised exercise within the context of living with COPD (Polgar & Thomas 2000). In this way, healthcare interventions tailored to the needs of people with COPD may be offered. Qualitative research methods are well placed to do this.

Prior to commencing the study, ethical approval to conduct research within the hospital needed to be sought. This is described below.

3.4 *Ethical Approval*

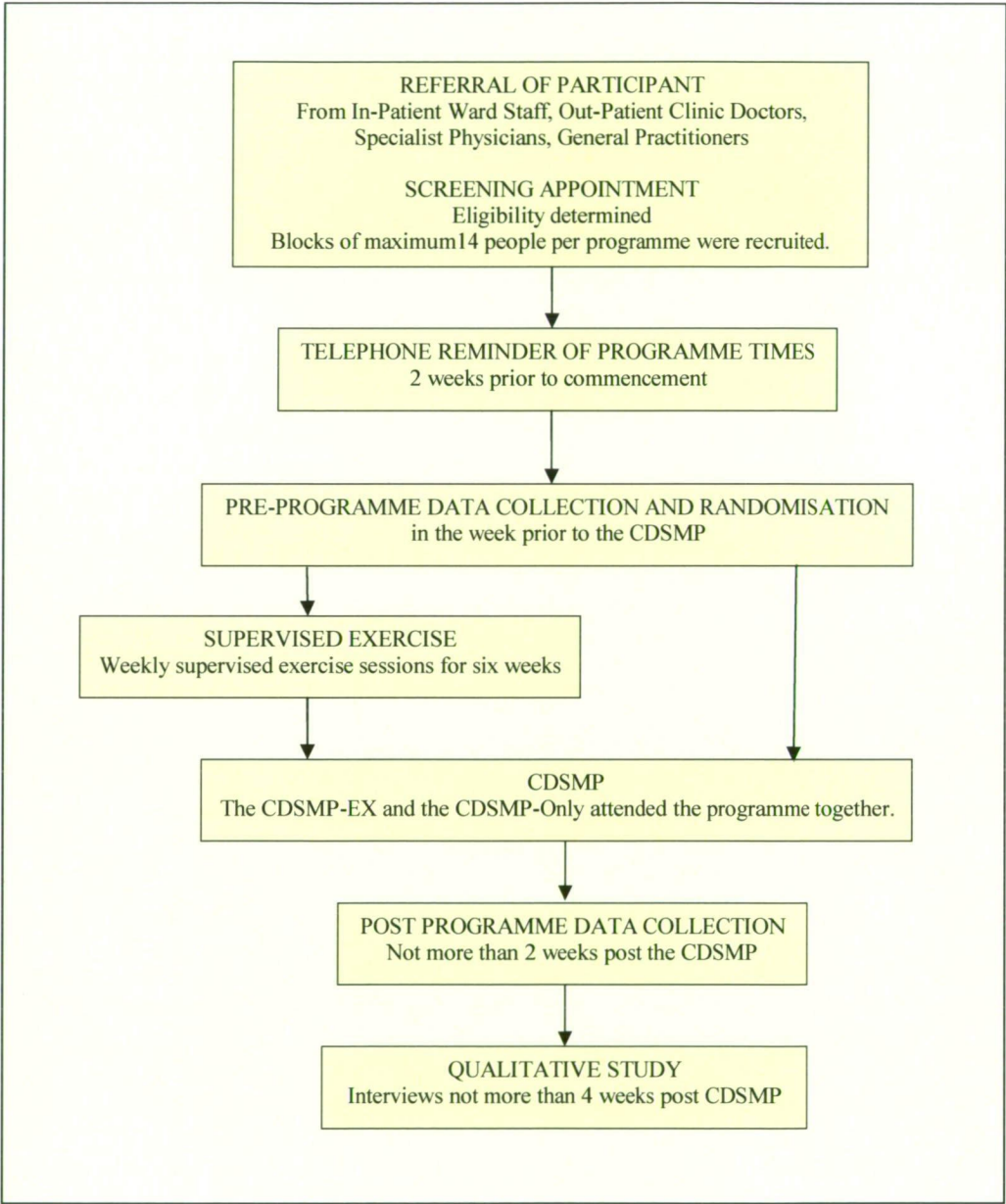
Before undertaking research and prior to submitting an application to the ethics committee, it was necessary to gain approval from the Clinical Support Services and physiotherapy managers within the study hospital. Discussions concerning the concept of undertaking a higher degree by research within the hospital were held with management in August 2003. As this was the first time PhD studies had been conducted within the Physiotherapy Department, managers requested that a departmental policy for proposals and procedures be finalised. A formal meeting was held in July 2004 between the physiotherapy manager, one of the PhD supervisors and the physiotherapist/student investigator who would be conducting the research. The newly devised Clinical Support Services Collaborative Research protocol and proposal forms were received in August, 2004. The proposal was submitted in September, 2004 and approval was granted.

A submission to conduct research within the hospital was approved by the hospital's Research Advisory Committee in October, 2004 and subsequently passed to the Human Research Ethics Committee of the study hospital and university. Ethical approval, reference number H0008105, was granted in December, 2004.

3.5 Study Steps

The study involved a number of steps that took place according to a time frame determined a priori (Figure 1).

Figure 1: Steps for the Study



3.5.1 The Study Setting

There were two phases of data collection. Collection of quantitative outcomes took place in the Physiotherapy Cardiopulmonary Out-Patients department of a metropolitan university affiliated hospital, from January 2005–March 2007. All

participants attended the CDSMP held in the same location. For the qualitative data collection, participants were interviewed at a location and time of their choice.

3.5.2 Participants

3.5.2.1 Recruitment

As the CDSMP was offered in a public hospital, participants required a referral from their General Practitioner (GP) or Specialist Practitioner if referred from outside the hospital. In-hospital referrals were from medical practitioners, allied health or nursing staff. Recruitment was from a number of sources, explained below.

GP Referrals for Participants with COPD

Personal letters (Appendix A.1), an information pack containing Participant Information (Appendix A.2) and the CDSMP brochure (Appendix A.3) were sent to general practitioners (GPs) in the hospital catchment area. Discharge letters to GPs also contained the CDSMP brochure.

Hospital and Specialist Referrals

At the hospital where the research was conducted the clinical pathway recommended for in-patients with COPD or who attend a Specialist Out-Patients' Clinic is referral to cardiopulmonary rehabilitation. Support from the Director of Respiratory Medicine and associated specialist private practitioners was in place prior to the research commencing. As the CDSMP was a new approach within the hospital, presentations detailing the CDSMP and the research were made to doctors as well as to allied health practitioners. New resident medical practitioners and allied health practitioners were reminded of the CDSMP at weekly meetings. Brochures highlighting the CDSMP (Appendix A.3) were placed on wards for distribution by staff and in out-patient waiting areas.

Medical Students

Seminars concerning care of people with chronic conditions, self-management and the CDSMP were conducted with the medical students, as part of their undergraduate curriculum. The referral process within the hospital was outlined as many of these students would subsequently work at the hospital following their graduation and would be in a position to refer participants to the CDSMP.

3.5.2.2 Inclusion Criteria

Participants were required to meet the following criteria:

- over 18 years
- willing to attend a supervised exercise component
- willing and able to commit to 8 weeks of programme attendance
- have a diagnosis of COPD based on airflow limitation measured by spirometry (McKenzie, Frith & Burdon 2003) or a physician diagnosis
- be at least 2 months post exacerbation. An exacerbation was defined as increased shortness of breath, increased mucus production, and purulent mucus (Bellamy, Booker & Fardy 2003; MacNee & Rennard 2004)

3.5.2.3 Exclusion Criteria

Participants were ineligible if they:

- had an intellectual disability
- were unable to provide informed consent
- were unable to complete a self-administered questionnaire
- were unable to safely undertake an exercise programme due to the presence of any one of the following conditions:
 - uncontrolled cardiac conditions
 - (resting systolic blood pressure > 180mm mercury and/or resting diastolic blood pressure > 110mm mercury, resting heart rate >120 beats per minute, unstable angina, severe cardiac valve disease, uncontrolled atrial or ventricular arrhythmias, uncompensated chronic heart failure, active pericarditis or myocarditis)
 - recent vascular conditions
 - (recent embolism or thrombophlebitis, active retinal haemorrhage, recent cerebrovascular accident)
 - uncontrolled metabolic disorders
 - (uncontrolled diabetes, retinopathy, acute thyroiditis, uncontrolled liver or renal disease, active cancer)
 - severe orthopaedic problems
 - acute systemic illness or fever (Balady 2000)

- had previously attended a CDSMP or a comprehensive cardiopulmonary rehabilitation programme, within the past two years.

3.5.3 Screening

All participants referred to the Physiotherapy Cardiopulmonary Out-Patients Department attended a screening appointment at which time any necessary education or additional intervention, such as secretion removal techniques, was undertaken. An Eligibility Assessment Form was devised (Appendix A.4) to document inclusion and exclusion criteria for the study. As this research was integrated into clinical practice, the assessments were conducted by either the investigator or a second physiotherapist who provided additional clinical hours. The screening appointment was at least one week prior to the pre-programme (baseline) data collection.

At this appointment particular information was obtained:

- Details of present and past medical history.
- Routine measures of blood oxygen saturation (SaO_2), heart rate (HR), blood pressure (BP) and weight.
- Safety to attend supervised exercise was ascertained according to the exclusion criteria.
- Condition-specific behaviours (breathing pattern and use of reliever medications were assessed, checking that appropriate vaccines have been administered and weekly weighing habit were discussed with patients and an agreed plan to address them was formulated if this was necessary.
- A 6-minute walk test (6MWT) with continuous SaO_2 and HR printout was performed to guide whether additional intervention, such as supplemental oxygen, may be required during exercise. As participants were therefore already familiar with the 6MWT procedure, it was unnecessary for the test supervisor to demonstrate the walk test or for participants to perform a practice walk test at the pre-programme data collection. There was at least one week between the screening assessment, at which the practice walk was performed, and the baseline data collection.

The study was explained and attendance at a CDSMP offered to all patients, with assurance that not participating in the study would not compromise any ongoing care.

Those who agreed to participate were given Participant Information (Appendix A.2). No written consent was sought at this stage, allowing participants to read and reflect upon the supplied information. It was reinforced that the objective of the study was to assess the intervention of supervised exercise; therefore no discussion concerning exercise could take place at this appointment. Following the CDSMP, those not randomised to supervised exercise were told they would have opportunity to attend a supervised exercise group if they wished to do so.

If patients declined the invitation to participate in the study or were found to be ineligible, the patient's goals pertaining to exercise were collaboratively ascertained and an exercise programme was developed with that individual. Participants were either invited to join the CDSMP with study participants or referral to another CDSMP in the hospital was arranged. Written attendance dates were given to all patients with the hospital's brochure about the CDSMP (Appendix A.3).

3.5.4 Telephone Reminder of Project Times

The physiotherapy assistant telephoned participants a maximum of two weeks prior to the CDSMP commencing to remind them of the attendance dates. Verbal confirmation of attendance was obtained. If the person no longer wished to participate, reasons were sought and a follow-up appointment made if this was indicated. They were still eligible to attend the CDSMP, irrespective of study status.

3.5.5 Pre-Programme Session

3.5.5.1 Informed Consent and Data Collection

At the first group session pre-programme data was collected. Written informed consent was obtained at this session. A single consent form was used for the quantitative and qualitative enquiry (Appendix A.5).

Name, address and demographic information: age, gender, ethnicity, education level, marital status, and chronic conditions (as defined by the participant) were recorded on the front cover of the pre-programme questionnaires. Name and address were recorded with the post-programme questionnaires (Appendix A.6).

Primary and secondary quantitative outcome measures were collected at the pre-programme session (Appendix A.6.1–A6.6). To avoid any socially desirable

response bias, the investigator did not collect any of the outcome data. The 6MWT was supervised by a physiotherapy assistant unconnected with the study and who recorded the data (Appendix A.7). The questionnaires were supervised and collected by a nurse.

The secondary outcome measures were collated into questionnaires, resulting in a large number of pages for participants to answer. Recognising this, time was spent re-explaining the importance of the information to the study. Participants were reassured they could take as much time as they wished to complete the forms. They were sincerely thanked again for participating in the study.

3.5.5.2 Randomisation

Consecutive patients referred to the CDSMP were recruited, with up to 14 participants able to be enrolled in each CDSMP. Randomisation occurred when pre-programme data was collected. Participants were allocated to the intervention groups using a random numbers table. As the participants randomised to the supervised exercise intervention attended the gym with other patients, the randomisation process needed to take this into consideration.

The confines of the gym meant that the numbers randomised to the exercise intervention were confined to up to seven participants at a time. Block randomisation was not used as this would limit participants to a group of seven at any time. The time frame of the study did not allow this. Therefore consecutive random numbers were used and the following process implemented.

If, during randomisation, the limit of seven was reached in one group, all other participants had to be allocated to the other group. Recognising that this process compromised true randomisation, resulting in pseudo-randomisation for participants, the following additional step was taken. The allocation was kept in separate opaque sealed envelopes until participants had completed the 6-minute walk test and pre-assessment questionnaires. Following this, a volunteer participant randomly selected one of the sealed envelopes, nominating CDSMP-EX or CDSMP-Only, similar to tossing a coin. In this way the two groups named in the envelopes were randomly allocated to the intervention or control groups. The investigator was blinded to the study allocation until participants were informed.

As previously mentioned, due to workplace constraints, the investigator was responsible for the supervised exercise group and so knew who attended the intervention. Thus there was a potential for the researcher’s expectations to influence the exercise group. This effect is known as a Rosenthal effect (Polgar & Thomas 2000). To counteract such an effect, a physiotherapy assistant not involved in the study or the CDSMP helped to supervise the exercise group. While it is recognised that this situation was not ideal, to enable this research to take place in the clinical setting and under the constraints imposed by the facility, it was unavoidable.

As the investigator also analysed the data, participants and study allocation were assigned an identification number that was entered with the data by the research nurse. Names, other identifying details and study allocation were kept separately to the identification numbers until study completion, maintaining blinding of the investigator during data analyses.

3.5.6 The Intervention: Supervised Exercise

The intervention was a supervised exercise session for 1 hour held during the same week of the CDSMP. In the absence of an exercise tolerance test, the intensity of exercise was determined by using the modified Borg Rating of Perceived Exertion (RPE) Scale (Borg 1982). A minimum of moderate intensity (RPE = 3) exercise was aimed for, in accordance with recommended guidelines (Australian Government Department of Health and Aging 2005). Participants were advised not to exceed a maximum intensity of RPE = 5. Therefore the exercise intensity was individualised for each participant between RPE 3 and 5. The parameters of the session are presented in Table 11 below.

Table 11: Parameters of Exercise

Frequency	Intensity	Time (duration)	Type
1 session per week	Aim for a moderate to strong intensity (Borg Scale: RPE = 3 to 5)	1 hour session. Aim for a minimum of 30 minutes of aerobic exercise	Aerobic, Stretching and Strengthening exercises for upper limbs, lower limbs and trunk

Participants were offered a choice of attending the supervised exercise session either in the morning prior to the CDSMP or later in the week. The first exercise session took place in the week of the first CDSMP session. In collaboration with the

physiotherapist/investigator, an individual exercise regime was determined. In accordance with Australian national recommended guidelines for physical activity, each session aimed to incorporate a warm-up and cool-down period, aerobic activity, stretching and strengthening exercises (Australian Government Department of Health and Aging 2005).

Within a one hour session, a guideline for time delineation (duration) was as follows:

- 5 minutes of warm-up exercises
- 30 minutes of aerobic exercise (bicycle , treadmill, corridor walking, bicycle arm pedals)
- 5 minutes of stretching exercise (upper limb, lower limb, and trunk)
- 10 minutes of strengthening exercise (upper limb, lower limb, trunk with free weights, pulleys, steps, elastic bands, or fit ball)
- 5 minutes of cool-down exercises.

This general guideline was adjusted according to individual needs. While recognising that 30 minutes of accumulated aerobic physical activity is only the minimum daily recommended amount, due to time constraints it was not possible to achieve a longer duration during the supervised exercise session. The above general exercise programme is the one in use in the hospital where the study took place, and is in accordance with cardiopulmonary rehabilitation guidelines (Nici 2007; Ries et al. 2007).

Exercise sessions were supervised by a trained physiotherapy assistant, with the physiotherapist readily available for consultation if needed. Physiological parameters (HR, SaO₂, BP) and exercise progress were recorded on an exercise record sheet used routinely in the gym (Appendix A.8). In keeping with our usual practice, participants were encouraged to complete their own record of the exercise programme, with assistance being provided as required. As self-reported physical activity was a secondary outcome measure for the whole study group no discussion regarding a home exercise programme occurred during the exercise session. There was discussion during the CDSMP about commencing a home exercise programme, but no specific programme was prescribed. Thus, all participants in the study received the same information concerning home exercise programmes.

3.5.7 Chronic Disease Self-management Programme

All participants — those allocated to the supervised exercise intervention and the control group — attended the CDSMP together and in the same week as the exercise sessions. The CDSMP is a 6-week programme with sessions of 2½ hours duration offered once per week and facilitated by pairs of trained leaders. The respiratory nurse and the investigator facilitated the programme and could both be seen as persons with whom participants with chronic conditions could identify. Both have family members with chronic respiratory conditions and the investigator has asthma, a chronic respiratory condition. As much as possible, the same leaders facilitated the CDSMP to ensure consistency of delivery style and personal interaction.

Although the CDSMP was revised in 2006, we continued to offer the 1999 version for the duration of the study. If someone did not attend the CDSMP or notify the leaders of their inability to attend, they were contacted by the physiotherapy assistant, to ascertain the reason for non-attendance.

The 1999 version of a course companion book, *Living a Healthy Life with Chronic Conditions* (LorigHolman et al. 1999) was lent to participants for the 6 weeks of the CDSMP. Purchasing details were supplied on completion of the programme for interested participants. This book is the only written information given to participants, as directed by the programme developers.

Additional patient information such as condition-specific information from the National Heart Foundation, Asthma Foundation, the Australian Lung Foundation, and National Prescribing Service, published brochures, booklets and videos were available from the patient display pockets at the venue. There was also information produced by various hospital health professionals. This included nutrition advice, exercise advice, suggested exercises and breathing techniques. In keeping with the principles of people learning to make informed choices, this information was not selected and handed out: participants were free to choose what suited their needs.

3.5.8 Post-Programme Session

3.5.8.1 Post-Programme Data Collection

At the eighth session, the week following the final CDSMP session, quantitative data collection was repeated, using the same procedure as at pre-programme data collection. All participants who had attended any of the CDSMP sessions completed the outcome measures. Those who had been unable to attend this session were contacted by the nurse and were invited to attend the following week to complete the quantitative data collection. Those who were unable to attend were considered to be withdrawals.

3.5.8.2 Invitation to Participate in Qualitative Study

At the eighth session participants were reminded of the qualitative arm of the research. They were given another copy of the research information sheet and invited to participate in the qualitative evaluation, the objective of which was to gain insight into the patient experience of attending the CDSMP±Ex.

Candidates were assured that their participation was purely voluntary and that their decision did not prejudice their relationship with their healthcare professionals. In the research design stage, it had been planned to provide participants with a consent form and a return-addressed envelope and invite them to return it should they wish to participate in the qualitative phase. This proved to be unnecessary; as participants indicated they had provided consent for the whole study at the pre-programme data collection and were happy to participate in an interview.

3.6 *Quantitative Study: Outcome Measures*

In considering the measures available to evaluate the effect of supervised exercise, consideration was given to the psychometric properties and to the relevance to our clinical practice. The measures selected to evaluate the primary and secondary outcomes are discussed in detail in this section.

For an instrument to be useful it must be valid and accurate. That is, it must measure what it is intended to measure (construct or content validity) and ideally correlate with another validated measure of the same construct (concurrent validity). It should also be reliable, providing consistent and accurate responses when used under the

same circumstances across multiple trials (internal consistency or reliability) and when used repeatedly by the same group of people (test–retest reliability) (Polgar & Thomas 2000). Indeed, others deem reliability to be of paramount importance, stating that if an instrument does not have demonstrated reliability, then it cannot be validated (Kriska & Casperson 1997).

If it is to be used as an outcome measure to test response to an intervention, it should also be sensitive or responsive to change (responsiveness). The change can be calculated as an ‘effect size’ (Cohen 1988; Kazis, Anderson & Meenan 1989). However, such change should be meaningful to the respondent and investigators, particularly if it is to inform clinical practice. The minimum change in a test result at which patients perceive they are either better (or worse) is known as the minimal clinically important difference (MCID) (Jaeschke, Singer & Guyatt 1989; Jones 2002).

Finally the instruments or tools need to be easy to use and relevant to the research questions (Polgar & Thomas 2000).

Where possible, tests with these established psychometric properties for the population with COPD being studied were selected. The above parameters are addressed with each measure described below. The meaning of the statistical tests used to interpret the parameters is presented, if interpretation has not been provided previously.

3.6.1 Physical Capacity: 6-Minute Walk Test

As previously explained, participants had been familiarised with the 6MWT procedure at the screening assessment. In accordance with the American Thoracic Society statement that a practice 6MWT is not usually necessary (American Thoracic Society, 2002), and supported by Sciurba et al. (2003), the protocol for this study was to familiarise participants with the 6MWT at screening assessment more than a week prior to baseline data collection.

The primary outcome was physical capacity, defined as the capacity to undertake the physically demanding activities of daily life. Physical capacity was measured by the distance walked in the 6-minute walk test (6MWT), a self-paced sub-maximal walking test (Guyatt et al. 1985). This test evolved from a 12MWT for assessing

capacity in people with chronic bronchitis (McGavin, Gupta & McHardy 1976), which itself was an adaptation of a 12-minute field test for healthy individuals (Cooper 1968). The 6MWT is simple to perform, does not require sophisticated equipment or training and is reflective of daily activities involving walking (American Thoracic Society 2002).

3.6.1.1 Procedure for the 6-Minute Walk Test

As previously explained, participants had been familiarised with the 6MWT procedure at the screening assessment. In accordance with the American Thoracic Society (ATS) statement (American Thoracic Society 2002) that a practice 6MWT is not usually necessary, and supported by Sciurba et al. (2003), the protocol for this study was to familiarise participants with the 6MWT at screening assessment more than a week prior to baseline data collection.

Participants were instructed to wear comfortable clothing and footwear for walking, to bring their usual walking aids, and to continue their usual medication regime. They were requested not to eat 30 minutes prior to the test, nor to have had any vigorous exercise two hours before the test (American Thoracic Society 2002). They were asked to carry reliever medication with them in the event it was required during the test. Supplemental oxygen was supplied if it was usually required for walking or exercising. The cylinder was carried by an assistant who walked behind the participant so as not to influence their walking speed.

Participants rested for at least 10 minutes before the test (American Thoracic Society 2002). Resting SaO₂ and HR were taken by a portable pulse oximeter and recorded. Resting BP was taken with a sphygmomanometer. The measurements were repeated post test. Perceived exertion post test was determined using the Borg Rating of Perceived Exertion (RPE) scale (Borg 1982). This same scale with dyspnoea descriptors was used to rate perceived breathlessness post walk. All data were recorded on an objective data record sheet (Appendix A.7).

Standardised instructions were given to the participant.

The object of the 6MWT is for you to walk as many lengths of this 25 metre corridor as you can in 6 minutes, without running. If you need to stop and rest, please do so, and then resume walking as soon as you are able to. I will count the number of stops. However, if you experience any jaw, neck, chest or arm pain; any nausea, dizziness or

unusual breathlessness; or severe headache please tell me and we will discontinue the test. Please walk back and forth between the strips on the floor and turn briskly on the strips. Do not talk during the test. When the timer beeps I will tell you to stop. Please stop right there and I will come to you. Remember, the object of the test is to walk as many lengths of the 25 metre corridor as you can in 6 minutes, without running. I will tell you when to start. Start walking now.

Timing was by a stopwatch that was preset at 6 minutes and counted backwards. The test supervisor marked each 25 metre length walked on the record sheet. At the completion of the test the total distance walked was recorded to the nearest metre, number of stops recorded and post-walk parameters (SaO₂, HR, BP, RPE and shortness of breath) recorded. Participants were asked to rate their RPE with the standard question: 'How much effort or exertion did you experience during the walk test?' We ascertained and recorded the reasons for stopping during the test and the limiting factors to walking further. Similarly, shortness of breath was recorded following the question, 'How much shortness of breath did you experience during the walk test?'

3.6.1.2 Determinants of Distance Walked

It is important that the 6MWT be performed in a consistent way, as the distance walked is influenced by a number of factors. Walking tests, as well as activities of daily living, are affected by the participant's motivation and cardiovascular, pulmonary and neuromuscular status (McGavin et al. 1977; McGavin, Gupta & McHardy 1976). While these intrapersonal variables cannot be controlled, controlling for other variables such as course layout and verbal encouragement is important.

Course Layout

The ATS Guidelines recommend a 30-metre straight course layout be used for the walk (American Thoracic Society 2002). In a multicentre trial others found that a continuous course resulted in longer distances walked than a straight course. However, their results also indicated that longer distances walked were not achieved with longer straight courses when compared with shorter courses (Sciurba et al. 2003). Indeed, the shortest straight course distance in their study was 50 feet (15.25 metres). We therefore used an existing 25-metre indoor straight walking course in the hospital. The course was located in a low-use well-lit and ventilated corridor and had a flat non-slip hard surface. It was marked every metre and turnaround points at the

zero and 25-metre mark were delineated by a highly visible insert, the width of the corridor, in the floor covering. A chair was placed at either end and at the halfway mark of the course, in the event that a participant needed to sit down.

Verbal Encouragement

Guyatt et al. evaluated the effect of verbal encouragement or no encouragement on distance walked. They found a statistically significant difference ($p < 0.02$), favouring subjects receiving verbal encouragement by a distance of 30.5 metres. However, they found that there was similar within subject variation with verbal encouragement (22.83 metres) or without verbal encouragement (22.25 metres). The authors concluded that consistency of approach was the most important factor and that verbal encouragement was at the discretion of the researchers. It was also found that the enthusiasm of the test supervisor during verbal encouragement could bias results, necessitating standardisation of encouragement and blinding of the supervisor to intervention allocation (Guyatt et al. 1984). The design of this research was to have the same test supervisor who was blinded to study allocation. Participants were not informed of allocation until all baseline measures were completed. However, contingencies could arise when another supervisor might need to be present. The ATS guidelines do suggest the use of verbal encouragement. However, as test supervisor enthusiasm could not be controlled, especially in the event of different supervisors, to maintain standardisation the decision was made not to use verbal encouragement (American Thoracic Society 2002).

3.6.1.3 Psychometric properties

Validity

The 6MWT has demonstrated construct and concurrent validity in that it yielded comparable results to the 12MWT, which also measures physical capacity for respiratory patients with Pearson's correlation coefficient indicating a strong correlation of $r = 0.96$ (Butland et al. 1982). The 6MWT was deemed more acceptable to the patients. Construct validity was demonstrated by a moderate correlation ($r = 0.58$) between distance walked and maximum work capacity during testing on a cycle ergometer (Guyatt et al. 1985).

Reliability

Reliability of the test was also established for this same group of patients with an intraclass correlation coefficient (ICC) of 0.921 for six walking tests, and 0.909 for walking tests three to six. The authors explain an ICC as a coefficient that ‘relates the variance between subjects to the total variance and kappa, which is a special case of the intraclass correlation coefficient for nonparametric data’ (Guyatt et al. 1985, p. 522).

Responsiveness

Changes in distance walked had a moderate correlation with changes in maximal oxygen consumption for elderly people with moderate COPD, $r = 0.64$ (Bernstein et al. 1994). This indicates moderate responsiveness.

Interpretation

Redelmeier et al. provided interpretation of the 6MWT by elucidating the minimal clinically important difference of 54 metres for adults with stable COPD. That is, a change of 54 metres was required for a person to rate a change, either better or worse, in their walking ability relative to their peers (Redelmeier et al. 1997).

With its functional applicability, ease of administration, validity, reliability, responsiveness and acceptability to patients, the 6MWT was selected as the measure to evaluate the primary outcome of change in physical capacity. In addition, it is a test used widely in the cardiopulmonary domain as a prognostic marker, a criterion for surgery and as an outcome measure for interventions (Guell et al. 2000; Lacasse et al. 2002; Monninkhof, E. et al. 2003; Pinto-Plata et al. 2004). It has been the test of choice for this group of patients at our hospital for some years.

The following outcome measures constitute the secondary quantitative outcome measures relating to self-reported physical activity, stage of change for exercise and self-efficacy for exercise, Health Related Quality of Life (HRQoL), shortness of breath, self-management behaviours and condition specific behaviours. (Appendix A.6.1—A6.6).

3.6.2 Self-Reported Exercise Questionnaire

In clinical physiotherapy practice a home exercise programme is recommended to patients and they are relied upon to report the outcome. Self-reported exercise is a health behaviour outcome reported in most CDSMP studies as discussed in *Chapter Three*. This research sought to evaluate the effect of supervised exercise with the CDSMP on self-reported exercise. (Exercise is used synonymously with physical activity in this thesis.)

3.6.2.1 Questionnaire Selection Criteria

When selecting a questionnaire to measure self-reported exercise Kriska and Casperson note that there is no gold standard. They point to a number of considerations that were followed in this research (Kriska & Casperson 1997). The following properties were sought:

- *Practicality*. For ease and consistency of administration, a self-administered test was preferable.
- *Applicability*. The test needed to be relevant to the population of adults with COPD in this study and cover a broad range of activities usually undertaken by an older age group of men and women.
- *Time frame*. As the people in this study live with conditions that can exhibit fluctuating symptoms from day to day, it was useful to ask about a 'typical' period of activity rather than a discrete time frame.
- *Derived outcomes*. The parameters of duration, frequency, and intensity were considered in light of the current recommendations for physical activity.
- *Psychometric properties*. Tests with established properties of reliability, validity and responsiveness were considered.

3.6.2.2 Exercise Questionnaires for Older Adults

There are a number of questionnaires specifically designed to measure physical activity, of which exercise is a component, in older adults. Those reviewed are presented in Table 12.

Table 12: Exercise Questionnaires for Older Adults

Questionnaire	Administration Mode	Activity Assessed	Recall Time Frame	Outcome of Activity
CHAMPS Community Healthy Activated Model Programme for Seniors (Stewart et al. 2001)	Self Telephone, Personal Interview	Recreational including sport/exercise, Household.	Typical week in the previous 4 weeks	Frequency per week, Duration per week, Intensity, Caloric expenditure
PASE Physical Activity Scale for the Elderly. (Washburn et al. 1993)	Self by mail, Telephone, Personal Interview	Recreational including sport/exercise, Household, Occupational	Previous 7 days	Activity Score
YPAS Yale Physical Activity Survey (DiPietro et al. 1993)	Telephone, Personal Interview	Recreational, Household, Exercise	Typical week in previous month	Duration per week, Energy expenditure per week, Activity score
Modified Baeck Modified Baeck Questionnaire for Older Adults (Voorrips et al. 1991)	Interviewer	Recreational including sport/exercise, Household	Previous 12 months	Activity score
Zutphen Zutphen Physical Activity Questionnaire (Caspersen et al. 1991)	Self	Recreational including sport/exercise	Previous week/month Usual	Caloric Expenditure

Of the self-administered questionnaires reviewed, the CHAMPS (Stewart et al. 2001) and the PASE (Washburn et al. 1993) are self-administered and cover the broadest range of physical activities. The CHAMPS identifies physical activity in a ‘typical’ week rather than a discrete week as measured by the PASE. It also measures the parameters of interest (frequency and duration of all and of moderate activity) whereas the PASE computes an activity score. It has acceptable psychometric

properties as discussed below. As the CHAMPS questionnaire satisfied the criteria set, it was selected from the reviewed self-reported measures (Appendix A.6.1.).

The CHAMPS self-report questionnaire consists of 41 questions, taking an average 10–15 minutes to complete. It measures caloric expenditure and self-reported physical activity for both moderate activity and for all reported activity in a typical week during the preceding 4 weeks. The questions relate to activities of daily living, recreational physical activity and typical exercises suggested in interventions for an older age group. Non-physical activities are included to minimise a socially desirable response from inactive individuals. The recorded physical activities can be analysed as ‘all’ physical activities, or a sub-group of moderate activities may be analysed. Recall is facilitated by use of recognition memory, that is, presenting specified activities, said to be preferable for older adults who may find recall difficult (Stewart et al. 2001). Impaired memory is recognised as an issue for people with COPD (Incalzi et al. 2003) so a test facilitating recall was deemed appropriate for this group.

3.6.2.3 Psychometric Properties of the CHAMPS Questionnaire

Validity

In an independent validation study, the CHAMPS questionnaire was validated against the criteria of 6MWT and the physical functioning domain of a HRQoL measure, the SF-36, for an older population (age range of 65–89 years) with arthritis, diabetes, cardiovascular and respiratory conditions. Pearson’s test demonstrated moderate correlations for the total sample between the CHAMPS and the 6MWT ($r = 0.46$) and the physical functioning domain of the SF-36 ($r = 0.39$) (Harada et al. 2001), indicating moderate concurrent validity. Sub-sample analysis by condition was not performed.

Reliability

The measure has moderate two-week test–retest reliability for ‘all’ physical activities, with a Pearson’s r and ICC of 0.62. Moderate intensity physical activities questions demonstrated high reliability, with a Pearson’s r and ICC of 0.76 (Harada et al. 2001).

Responsiveness

The CHAMPS has been found to be responsive to change in caloric expenditure with physical activity (Stewart et al. 2001). In an older group of people with COPD who may not be very active, it is important that a measure is able to detect even small changes in physical activity in response to an intervention. Stewart et al. noted that the CHAMPS was sensitive enough to detect a small effect size of 0.38–0.42 for caloric expenditure. The questionnaire was also responsive to small changes in self-reported physical activity, with a moderate effect size of 0.54–0.64 (Stewart et al. 2001). A value of 0.20 to 0.40 signifies a small effect, 0.50 to 0.7 a moderate effect, and 0.80 or greater a large effect size (Cohen 1988; Kazis, Anderson & Meenan 1989).

Interpretation

While assessing the range of intensities of activity from light to vigorous, the CHAMPS questionnaire focuses on moderate intensity physical activity, an example of which is 'play golf, carrying or pulling your equipment'. This is in keeping with recommended guidelines for the adoption of moderate physical activity (Australian Government Department of Health and Aging 2005). Interpretation with respect to intensity, frequency and total duration per week was benchmarked against the Australian national criteria of achieving a minimum total of 150 minutes of moderate physical activity per week, preferably by exercising for a minimum of 30 minutes per day on at least 5 days of the week.

In summary, the CHAMPS questionnaire has demonstrated moderate construct validity, moderate reliability and is responsive to change, even when that change is small. It is designed to facilitate recall of usual activities for an older age group, and may be interpreted in the light of current national and clinical guidelines for physical activity. It is easy to administer. Thus it was selected as a measure of self-reported exercise for this research.

3.6.3 Exercise Participation and Stages of Change

Prior to measuring stage of change, a question pertaining to criteria for exercise participation was asked. It was a prelude to the validated stages of change questionnaire described below (Appendix A.6.2.)

In *Chapters Two and Three*, it was reported that the CDSMP aims to enhance self-efficacy, a construct of health behaviour change theories such as the transtheoretical model of change. It was postulated that the CDSMP might promote progression along the stage of change continuum. There is scant reference to the influence of supervised exercise with the CDSMP on stages of change for exercise in the literature. Therefore, stage of change for exercise was measured.

Exercise: Stages of Change–Short Form questionnaire, from the Cancer Prevention Research Center (www.uri.edu/research/cprc/Measures/Exercise02.htm), was used to measure this outcome (Appendix A.6.2). Respondents answer ‘Yes’ or ‘No’ to a criterion question before marking one of five stage-related statements.

3.6.3.1 Questionnaire Selection Criteria

The questionnaire fulfils the considerations for staging algorithms suggested by Reed et al. when assessing stage of change (Reed et al. 1997):

- *It encompasses the five stages of change* (precontemplation, contemplation, preparation, action and maintenance).
- *It addresses a defined behaviour* (exercise) with *criteria* of frequency, duration and intensity clearly stated. These criteria were modified (with permission) to reflect the Australian recommended guidelines for minimum physical activity per week, that is, moderate intensity exercise on all or at least 5 days of the week accumulating 30 minutes or more per day (Australian Government Department of Health and Aging 2005).
- *Examples of common activities* which might be undertaken in meeting the exercise criteria are given.

The format has five possible selections relating to stage, with participants marking the statement that applies best to them.

3.6.3.2 Psychometric Properties

Validity

Support for construct validity for the stages in the adoption of exercise has been demonstrated by a positive linear relationship between the mean scores of self-reported physical activity and stage, and estimated cardiorespiratory fitness and stage

for 235 younger adults (Cardinal 1997). Cardinal (1997) did not focus on people with a particular condition. A significant increase in weekly duration of exercise and in energy expenditure with progression through the stages was noted for 349 older people following cardiac rehabilitation. (Hellman 1997). Support for Hellman's (1997) research has been extended by others who found similar increases in self-reported physical activity and movement through the stage continuum for a group of patients with an average age of 60.3 years in a cardiac ($n = 35$) or a pulmonary ($n = 5$) rehabilitation programme (Guillot et al. 2004).

Reliability

Test-retest reliability over a two-week period for 20 healthy middle-age employees was established with a Kappa index of $K = 0.78$. The Kappa index is a correlational index, with a high correlation being above 0.75 (Marcus, Banspach et al. 1992).

Interpretation

The questionnaire may be interpreted as number of stages progressed or regressed, as percentage of participants at combined pre-action stages versus combined action stages, or as percentage at each stage (Nigg 2002). As the area of interest was to determine at what stage of change for exercise participants presented to the CDSMP, and what effect the CDSMP may have on stage progression, it was decided to interpret the results in terms of percentage at a particular stage pre and post intervention.

At the time of selecting outcome measures (2003), the psychometric properties for the stage of change measure did not appear to have been widely validated for people with COPD. A recent study established the psychometric properties of the scale for a Chinese population attending the CDSMP but did not state if this included people with COPD (Chan et al. 2007). However, this model has been drawn upon when designing interventions for people with chronic conditions, and is referred to when discussing health behaviour change (Kelly, Menzies & Taylor 2003; Lidner et al. 2003). It was therefore decided to utilise the available tools at the time to evaluate stage of change for exercise.

3.6.4 Exercise Self-Efficacy

The CDSMP is structured to facilitate self-efficacy development. Skills mastery is a source of self-efficacy information. Therefore, would the addition of supervised exercise provide greater mastery experiences, resulting in increased self-efficacy for exercise?

Exercise self-efficacy was assessed with the Exercise: Self-Efficacy Measure (www.uri.edu/research/cprc/Measures/Exercise04.htm) (Appendix A.6.3). There are six domains relating to barriers to exercise, scored on a five-point Likert scale, ranging from '1 = Not at all confident' to '5 = Completely confident'. The six-item measure has been expanded to an 18-item measure with three questions per domain. The 18-item measure was selected for this study, as it yields more detailed information.

3.6.4.1 Psychometric Properties

Validity

There appears to be little published information concerning the construct validity of this scale, either in a general population or for specific health conditions.

Interpretation

The scale is scored by taking the average of the items, with a higher score indicating a greater level of exercise self-efficacy. The minimal clinical important difference for this scale has not been determined. However, it is suggested that one-third of a standard deviation for the group investigated be considered as clinically important (J. Rossi 2007, email, 10 October, <jro3627u@postoffice.uri.edu>).

Reliability

The original 5-item measure was found to have high reliability over a two-week interval when test–retest reliability was evaluated by Marcus et al. (1992). The product–moment correlation coefficient was 0.90, for a group of 20 young adult medical centre employees.

As with the stage of change for exercise measure, there is little published information concerning its reliability for people with COPD. Nevertheless, it was decided to use this available scale.

3.6.5 Shortness of Breath

Shortness of breath is a debilitating symptom for people with COPD but it is not included as an item measure in the Short Form 36 Questionnaire Version 2 (SF-36v2) used in this study to evaluate quality of life. (The SF-36 v2 is discussed in the following sub-section.) It was therefore considered necessary to capture more information about the severity and frequency of this symptom. Furthermore, the CDSMP teaches cognitive symptom management techniques. Thus the effect of the CDSMP with or without supervised exercise on participants' perceptions of severity and frequency of shortness of breath, was also evaluated.

The Visual Analogue Scale (VAS) was used to measure shortness of breath with respect to severity and frequency in general (Appendix A.6.4). The VAS is a 10-centimetre line that may be oriented vertically or horizontally (American Thoracic Society 1999). For this study, a horizontal orientation was used, to be in keeping with the layout of the other questionnaires. While there appears to be no standardisation of phrases, the VAS is anchored at either end by descriptors that reflect the dimensions of shortness of breath being measured. The following descriptive anchors were used, as suggested by the ATS: 'no shortness of breath' to 'shortness of breath as bad as can be' for severity; and 'none of the time' to 'all of the time' for frequency. The scale is easy to use, with respondents simply marking the scale to indicate the degree of severity or frequency of breathlessness. It is then scored by measuring from the left-hand end of the scale to the point indicated by the participant (American Thoracic Society 1999).

3.6.5.1 Psychometric Properties

Validity

A strong negative correlation with forced expiratory volume in one second (FEV1) has been reported, supporting the construct validity of the VAS as a measure of breathlessness. Pearson's r was 0.84 for white Americans and 0.89 for African Americans in a cross-sectional study (Hardie et al. 2000). The authors state that this is congruent with the expectation that perception of severity of breathlessness would increase with decreasing FEV1, which is a robust measure of lung function, and may indicate increasing airflow obstruction.

Reliability

There is little reference to the reliability of the VAS in the literature.

Responsiveness

A decrease in shortness of breath for patients with COPD or asthma following a cardiopulmonary rehabilitation programme has been demonstrated, indicating the responsiveness of the VAS as an indicator of shortness of breath following interventions. However, effect sizes were not reported to indicate the magnitude of the response (Foglio, Bianchi & Ambrosino 2001). A 20-centimetre VAS (enlarged to accommodate the study protocol), detected a change in shortness of breath as a result of exercise training (Carrieri-Kohlman et al. 1996).

Interpretation

While the VAS has been used to detect changes in shortness of breath, it is useful to know what constitutes a meaningful change to the person who is breathless. The MCID in VAS scores for people experiencing an acute episode of heart failure was shown to be 2.1 centimetres (Ander et al. 2004). Similarly, the minimal clinical important difference for a group of people with an asthma exacerbation was 2.2centimetres (Karras, Sammon & Terregino 2000). The minimal clinical important difference for people with COPD appears not to have been elucidated to date.

A visual numeric to measure shortness of breath is reported in self-management studies (Fu et al. 2003; Lorig, Sobel et al. 1999; Lorig et al. 1996). While the authors note that they have found this scale easy to use (Lorig et al. 1996), the psychometric properties have not yet been published. It was therefore decided to use the VAS, a tool with demonstrated validity and responsiveness.

3.6.6 Health-Related Quality of Life: SF-36v2

Physiological measures such as FEV1 or functional measures such as 6MWT are weakly associated with health-related quality of life (Kaplan et al. 2004; Mahler & Mackowiak 1995; Tsukino et al. 1996). People with similar severity of COPD may experience quite a different impact on their lives (Curtis & Patrick 2003), which is not captured by biomedical measures. Standardised health-related quality of life questionnaires measure this impact in a quantitative way (Jones 1995). This data then

adds to an understanding of the effect of interventions, such as the CDSMP with or without supervised exercise, on the lives of those whom we seek to help

Health-related quality of life was evaluated with the Short-Form 36 Questionnaire Version 2 (SF-36v2) (Appendix A.6.5). The SF-36v2 was released in 1996, reflecting improvements on the original SF-36 questionnaire (Ware, Kosinski & Dewey 2000). It measures the impact of co-morbidities people may have, not only that of COPD. This is an important consideration for the older individuals participating in my study, many of whom live with more than one chronic condition (Hoffman 1996). The SF-36v2 is a generic self-administered questionnaire with 36 items, taking 5 to 10 minutes to complete. It is suitable for individuals aged 14 years or over and has been found to be highly acceptable (McHorney et al. 1994). With the exception of self-reported health transition, the items are grouped in lots of two to ten to form eight scales, with each item being used only once. These scales measure physical function, role physical — a measure of the physical limitations on work or activities of daily living, bodily pain, general health, vitality, social functioning, role emotional or the effect of emotional problems on work or activities of daily living, and mental health. The scales themselves are divided into two summary components, the physical component summary comprising physical function, role physical, bodily pain, general health; and the mental component summary contributed to by the vitality, social functioning, role emotional, and mental health scales.

Changes incorporated into the SF-36v2 include formatting and word changes. Importantly, changing the dichotomous 'yes/no' response to a five-choice response in the role physical and role emotional scales has reduced ceiling and floor effects, reduced the variance and improved the internal consistency and reliability. Instead of the former 0–100 scale scoring system, norm-based scoring has been introduced, to give a mean of 50 and a standard deviation of 10 in the general United States population. As the population norm is included in the scoring algorithm, all scores can be immediately compared with the United States population norm. Norm-based scoring is also used for the eight scales and the two component summary measures, enabling direct comparison with each other (Ware, Kosinski & Dewey 2000).

3.6.6.1 Psychometric Properties

Validity

McHorney et al. demonstrated construct validity for the physical and mental health constructs, finding a high correlation between the physical component and physical functioning, role physical and bodily pain scales. Similarly, they found a high correlation with the mental health component and mental health, role emotional and social functioning scales (McHorney, Ware & Raczek 1993). They also tested the different scales across different patients grouped according to severity of condition (medical or psychiatric) and the coexistence of medical and psychiatric conditions. The mental health scale was the most valid for detecting the impact of psychiatric conditions and in discriminating that from serious medical conditions. Physical functioning was the most valid scale in detecting the impact of medical conditions in people who also had a psychiatric condition. This discriminative ability was important for the present study, as people with COPD often experience anxiety and depression as co morbidity.

In the COPD population, Kaplan et al. (2004) added to the validity studies. They recently observed low but significant levels of correlation between the SF-36 and 6MWT, with Pearson's $r = 0.19$ for the physical component summary and 0.17 for the mental component summary (Kaplan et al. 2004).

Reliability

In 1994, McHorney and colleagues extended studies of the psychometric properties of the SF-36, specifically evaluating reliability. They concluded that while missing data overall was low, those of older age, from a lower socioeconomic background and females were more likely to have incomplete data. As the study reported here drew participants from a predominantly older population from a diverse socioeconomic background, this finding alerted us to the need to be especially vigilant when checking for data completeness. The finding by the investigators of substantial 'floor' effects for role physical and role emotional with older people was also of concern to the present study. However, as noted above, the SF-36v2 has shown reduced floor effects for these scales. Internal-consistency reliability for each scale was high, with a Cronbach's alpha coefficient of 0.78 to 0.93. The authors note that the recommended minimum score for group comparisons is 0.50 to 0.70

(McHorney et al. 1994). Recently, Ware has indicated that the minimum score be 0.70 when evaluating the SF-36 (Nunnally 1978; Ware 2004).

Harper et al. tested reliability over a 6-month recall time in an observational study with 156 participants. Physical functioning and mental health were the most reliable of the SF-36 scales with an ICC of 0.86 and 0.74 respectively. Role emotional had the lowest score of 0.16 (Harper et al. 1997).

Responsiveness

Responsiveness of the SF-36 to clinical interventions was summarised by the authors at Quality Metric. After reviewing 42 randomised-controlled clinical trials across disorders, they concluded that the SF-36 is responsive to changes in health status following surgical, pharmacological or educational interventions.

Responsiveness has been evaluated in the COPD population. Sensitivity to change of the SF-36 was compared with that of condition-specific measures of health-related quality of life. Some authors are of the opinion that condition-specific measures of health-related quality of life may be more sensitive in detecting change in health status (Yusen 2001). However, an earlier study by Jones et al. concluded that both a self-administered condition specific measure, the Saint George's Respiratory Questionnaire (SGRQ), and the generic SF-36 were looking at similar health issues and that both measures reflected changes in health-related quality of life due to treatment (Jones & Bosh 1997). The SF-36 and the SGRQ are both capable of detecting even small changes in people with COPD (Jones & Kaplan 2003) and in detecting significant differences following pulmonary rehabilitation (Griffiths et al. 2000; Kaplan et al. 2004). Indeed, there was no evidence that the SGRQ was more responsive than the SF-36 in detecting change following cardiopulmonary rehabilitation (Kaplan et al. 2004).

Interpretation

The researchers at Quality Metric deem a five-point change in scores to have clinical, social and economic implications. By using norm-based scoring wherein the standard deviation equals 10, a five-point change in scores is equivalent to an effect size of 0.5, or a moderate effect (Lincoln 2000).

It would appear that the SF-36 is a valid, reliable and responsive measure for health-related quality of life in the COPD population. No studies were located that had used the SF-36v2 with the COPD population. In addition, use of the SF-36v2 enables benchmarking against population norms and takes into account the impact of co-morbidities on an individual. Therefore arguments have been presented for the use of the SF-36. The SF-36v2 has documented improvements on the SF-36 (as discussed above). Therefore the SF-36v2 was selected as the instrument for measuring health-related quality of life in this study.

3.6.7 Self-Management Behaviours

The CDSMP aims to help people develop self-management skills, so a decision was made to measure changes in generic self-management behaviours. The Partners in Health Scale (PIH scale) was used to measure what Battersby and colleagues (2003) consider core generic health-related self-management skills. The initial 11-item tool (Battersby et al. 2003) has been expanded to 14 items. Individuals self-rate their level of self-management on this 14-item questionnaire, using a 0 to 8 scale. For this scale, 0 represents worst self-management practice and 8 best practice (M. Battersby 2005, email, 23 March, <CCT005@fmc.sa.gov.au>) (Appendix A.6.6).

3.6.7 Psychometric Properties

Validity, Reliability and Responsiveness

A preliminary evaluation of the psychometric properties of the original 11-item PIH scale was completed by the authors for people with chronic conditions, including respiratory conditions. The authors did not state whether or not this included those with COPD. Construct validity was demonstrated with a factor analysis, and internal reliability was demonstrated with a Cronbach's alpha coefficient of 0.88 ($n = 46$). Responsiveness was not discussed (Battersby et al. 2003). Psychometric properties for the 14-item version have not been published.

Interpretation

The scale is scored by taking the average of the items. As noted above, a higher score on the PIH represents a greater degree of health-related self-management practice and a lower score indicates a lesser level of self-management practice. What constitutes a meaningful change in score has not been reported.

3.7 Analyses

As the quantitative data collection preceded the qualitative data gathering, the quantitative methodology is presented first. This does not signify that one is more or less than the other in terms of importance to the study.

3.7.1 Handling Missing Data

Data were analysed on an intention-to-treat basis, using a statistical software package, SPSS version 15. Data was inspected to detect percentage of missing data by examining frequency tables. Any pattern to the missing data was determined by running a missing data analysis to identify the participant(s) and then by checking the raw data. In addition, reasons for not completing variables were collected, enabling a determination as to whether the missing data was systematic or related to the variable. For example, the participant declined to answer because they saw no relevance of the question to them; missing completely at random, that is, the missing data was unrelated to the variable as in the case where a person does not complete data due to illness; or missing at random wherein the missing data is related to other variables but not the one with missing data (Fox-Wasylyshyn 2005).

Missing data for cases was not imputed. For those who withdrew, the baseline data was carried forward to the post data, unless the authors of a measure specifically stated that missing data should be dealt with in a particular way. This was the situation for the CHAMPS self-report of physical activity. The authors stipulated that all missing data (variable and item) be scored as zero (Stewart et al. 2001).

Missing items were imputed in the following way. For the SF-36v2, as suggested by the authors, when at least 50% of the items have been answered, case-mean substitution, using the final item values as defined by the authors, may be used to compute missing items (Ware, Kosinski & Dewey 2000). For other scale variables, when up to 20% of items were missing systematically or randomly, the item mean score was computed (Fox-Wasylyshyn 2005). For categorical variables it was not possible to compute an item mean score, therefore the baseline score was recorded.

3.7.2 Determining Data Distribution and Significance

Descriptive statistics were used to initially examine the range of data scores and to detect any values at the extremes. Visual inspection of the data using scatter plots and box plots on which the outliers were identified was also used. Values were checked, and a determination of whether or not these were likely to be true values was made.

The shape of the distribution curve, skewness with standard error of the skew statistic, the Kolmogorov-Smirnoff test and proximity of means with standard deviations or medians with ranges were used to determine normality. A skew statistic of more than twice its standard error, and a Kolmogorov-Smirnoff value of less than 0.05 suggest a departure from a normal distribution (Pallant 2005).

With the exception of exercise criterion and stage of change, which measured nominal data, all other outcome measures provided continuous data.

3.7.3 Comparisons: Quantitative Study

3.7.3.1 Baseline Characteristics

The following comparisons of baseline characteristics were made to determine any bias with respect to not participating in the study between the following groups:

- screening appointment attendees versus non-attendees
- study participants versus non-participants
- completers versus withdrawals.

Additional comparisons were made between:

- study participants versus the balance of the referred population, to determine if the sample in this study matched the population from which it was drawn
- intervention versus control groups, to determine the effectiveness of randomization and ascertain the presence of confounding variables.

3.7.3.2 Attendance Rates and Reasons for Attrition

Exploratory analyses investigated attendance rates for the CDSMP and supervised exercise sessions. Reasons for attrition were compared between these two groups.

3.7.3.3 Intervention Effect

To determine the effect of the intervention, the following comparisons were made:

- The CDSMP with supervised exercise (CDSMP-Ex) and the CDSMP without supervised exercise (CDSMP-Only) with respect to within and between-groups change in distance walked in 6 minutes (6MWD), self-reported exercise, self-efficacy for exercise, exercise participation (achieving exercise criterion), stage of change for exercise, shortness of breath, health-related quality of life and self-management behaviours.

3.7.3.4 Interviewees versus Non-interviewees

Comparisons were made to determine if the sample interviewed for the qualitative enquiry was similar to those who participated in the study:

- baseline demographic data of the two groups was compared.
- the baseline and post-programme outcomes of the interviewed participants were also compared to provide an additional element of triangulation: do the quantitative and qualitative data provide support for each other?

3.7.4 Statistical Tests

Two-sample t tests were used to compare the mean difference in change in variables between the intervention (CDSMP-Ex) and control (CDSMP-Only) groups for normally distributed data.

- Mann-Whitney U tests were used for data not normally distributed.
- Chi-squared tests were used to test the difference in proportions across categories for nominal data. Significance for statistical tests was set at a p-value of less than 0.05. Data were reported as medians with ranges or means with standard deviations.
- Effect sizes were calculated for the change in all outcome measures.
- Effect size was calculated by dividing the difference between the mean change for the CDSMP-Ex or the CDSMP-Only outcomes by the standard deviation at baseline of the outcome in question. That is, effect size = mean two - mean one divided by standard deviation one. Effect size is a mathematically derived standard measure enabling comparison of change

between or within groups (Kazis, Anderson & Meenan 1989). According to Cohen, a value of 0.20 to 0.40 is considered to be small, 0.50 to 0.7 is moderate, and 0.80 or greater indicates a large effect size (Cohen 1988).

- Univariable linear regression analyses were performed to explore the association between the change in 6MWT distance and the selected variables of age, gender, body mass index, education, breathlessness, exercise participation, the physical and mental component summaries of the SF-36v2 questionnaire and exercise self-efficacy. These variables were selected because of the reported influence of age, gender, height and weight which combined give the measure body mass index, on the 6MWT distance in healthy older adults (Enright et al. 2003). Additionally, the frequency and duration of exercise undertaken; exercise self-efficacy and degree of breathlessness would be expected to impact on the change in distance walked.
- Pearson's r correlation coefficients were inspected to determine if an association between the independent variables and 6MWT distance existed. Correlations can range from -1 to +1, with 1 being a perfect correlation and 0 indicating no correlation. Values less than 0.3 are accepted as indicating a weak correlation, 0.3 to 0.7 as moderate, and over 0.7 as high (Polgar & Thomas 2000).

If an association existed between the change in 6MWT distance and selected variables, the presence of confounding was determined by entering each variable in turn in univariable regression analyses as a function of study allocation (intervention group or control group) on the change in 6MWT distance. As the sample size had not been calculated for the secondary outcomes it may have been too small to detect a significant association. Therefore all biologically plausible variables were entered.

A multiple linear regression model was built following the analysis to detect confounding of the primary outcome, to investigate baseline predictors, that is which factors best explained the variance in the change in 6MWT distance (Bowers 2002). Although significance for standardised coefficient, β , was set at 0.15, because the sample size was small variables that caused a change of 10% or more in the study allocation variable and could plausibly have done so on biological grounds were also retained. The variable with the greatest effect from each set of similar variables was selected for the model. The variable with the smallest and/or significant p-value for

the unstandardised coefficient, β , was entered first, and regression analyses performed, resulting in the starting model. Forward selection was used to add variables with increasing p-value to the model. They were retained if statistically significant, biologically plausible or there was a 10% or greater change in any other variable in the model, as this would indicate confounding (Bowers 2002).

3.8 *Power Calculations*

Power calculations determine the number of participants required for a study. As (Bowers, 2002, p 135) states, ‘...the power of a test is... a measure of its capacity to reject the null hypothesis when it is false; in other words, to detect an effect if one is present.’ The number of participants required for the study was determined by calculations performed to detect a change in the primary outcome measure, the 6MWT. The minimal clinically important difference, or level of clinical significance for 6-minute walk tests is accepted as 54 metres (Redelmeier et al. 1997). The mean pre programme 6-minute walk distance in a pilot study was 365 metres, with a standard deviation of 74 metres. With a mean difference of 54 metres, power of 0.8, a level of significance of 0.05, and two-sided t test, the study required 31 participants in each arm to be confident of detecting a significant difference between the groups. With a drop-out rate of 25% (pilot study), it was calculated that 78 participants needed to be recruited to the study.

3.9 *Qualitative Research Methodology*

3.9.1 Introduction

This section details the qualitative approach used to gather the data and listen to the voice of our participants following their experiences of the CDSMP with or without supervised exercise. In keeping with the style of qualitative research books and articles, this section is presented in the first person (Hansen 2006).

While there is a strong history of qualitative research in the sociological literature concerning life with chronic conditions and issues of importance from the participant perspective (Bury 1982; Charmaz 1983, 1987; Corbin & Strauss 1987; Corbin & Strauss 1988; Radley & Green 1987; Williams 2000), it is relatively recent in the COPD rehabilitation-related publications (Monninkhof et al. 2004). There is scant

reference to participant experience of attending a CDSMP with or without supervised exercise. Gaining insight into the experience and what is important to the person with COPD who attends such an intervention, as well as quantitatively measuring health-related outcomes, is vital if our clinical practice is to be informed by a strong evidence base. A holistic focus that qualitative enquiry brings enables us to see the many personal views of supervised exercise and the CDSMP as portrayed by the participants. In synthesising the 'multiple realities' (Polgar & Thomas 2000), an understanding of why some people respond to an approach and others do not may be gained. This then aids an understanding of behaviour change as people learn to self-manage, and helps us to deliver interventions appropriately tailored to participants' needs.

3.9.2 The Sample

Fourteen men and six women were 'purposefully' invited to participate in the qualitative evaluation after attending the CDSMP with or without supervised exercise. In purposeful sampling participants are deliberately selected to yield data that is rich in information (Patton 2002). My logic in using purposeful sampling was twofold.

First, I wished to capture any themes that ran across cases while at the same time allowing individual differences in participant experience to be explored. Therefore I employed heterogeneous sampling (Patton 2002). I invited a selection of interviewees that enabled the group to be represented with respect to a range of education levels, marital status, disease severity, gender and their participation in the control or active intervention (supervised exercise).

Sampling with respect to a range of attendance status proved to be difficult. Most participants who attended less than four sessions were unwell. Only one person in this group was able to be included in the 20 interviews. Of those who did not start or who withdrew just after commencing the programme, only one of the five participants approached agreed to be interviewed. The data from that interview is woven into the findings from those interviewed who completed outcome data collection.

Secondly, I included six of the eight participants who had attended rehabilitation programmes previously, in order to gain their perspective of those programmes as well as the CDSMP. Two participants were unable to be interviewed, one due to ill health (control group) and the other to work commitments (intervention group). Those interviewed were invited to talk about their recollections of the programmes, not being directed in any way for this part of the interview, as I did not wish to influence their responses. I was especially careful to reassure the participants that I welcomed their unbiased feedback concerning their previous experiences.

Table 13: Participant Characteristics

Age (years)	Gender	Intervention Control	Marital Status	Maximum Education Level (years)	Duration of COPD since Diagnosis (years)	Severity
56	Female	Intervention	Married	9	2	Moderate
67	Female	Control	Widowed	8	16	No record
54	Female	Intervention	Separated	10	1	Mild
64	Female	Control *	Divorced	10	10	Severe
57	Female	Control *	Divorced	9	7	Severe
66	Female	Control	Divorced	12	30	No record
58	Male	Intervention	Divorced	11	5	Severe
55	Male	Control	Married	9	5	Severe
72	Male	Control *	Married	10	20	No record
72	Male	Control	Married	12	2	Severe
56	Male	Intervention	Married	12	18	Moderate
60	Male	Intervention	Married	12	0.5	Severe
65	Male	Intervention	Married	12	5	Severe
57	Male	Control	Married	12	2	Severe
76	Male	Control	Married	12	7	No record
81	Male	Intervention *	Married	11	20	No record
63	Male	Intervention **	Married	10	10	Moderate
70	Male	Intervention	Married	12	5	Moderate
73	Male	Intervention ***	Married	8	10	No record
57	Male	Intervention	Divorced	8	10	Mild
Average=64 years	Males=14 Females=6	Intervention=11 Control=9	Married=13 Divorced=5 Separated=1 Widowed=1	3 @year 8 or below 7 @year 10 or below 10@ year 12 or below	Average=9.3 years	Mild=2 Moderate=4 Severe=8 No record=6

Legend: * = attended cardiopulmonary rehabilitation more than 2 years previously; ** = attended cardiac rehabilitation programme previously; *** = attended CDSMP more than 2 years previously.

Sampling continued until the data was saturated, that is, the data analyses ceased to tell anything new (Patton 2002; Strauss & Corbin 1998). This point was arrived at after 14 interviews. To confirm data saturation, an additional six interviews were conducted. These were analysed against the established codes, being alert to new

information. As the data were not revealing new insights, interviewing ceased. The final sample therefore comprised 14 men and six women. Table 13 above depicts the participant characteristics.

3.9.3 Theoretical Tradition

Going to the participant and gathering data in their environment is described as field-based research. Field-based research personalises and puts into context the data obtained in the quantitative phase of the study (Babbie 1999; Grbich 1999; Patton 2002). I sought to explore the participants' insights after they had attended the CDSMP with or without supervised exercise. Therefore a cross-sectional rather than a longitudinal design was employed to gather the stories the participants told about these experiences. This posed a question for me: What field-based approach would best aid the discovery of what was important to my participants?

Prior to answering this question, I will clarify the terminology I will use. In this thesis I will use Patton's term, 'theoretical tradition' because it most aptly describes the particular ways of conducting qualitative research, governed by accepted rules or theories that have been handed down to create a tradition of inquiry. I will use the term 'method' to describe the process followed to investigate the research questions for this study (Patton 2002).

The theoretical tradition chosen for my research was influenced by the questions posed and the final purpose of the findings, for example, whether or not the intent was to derive theory or to understand experience (Morse & Richards 2002; Patton 2002). There are a number of theoretical traditions directing data collection in qualitative research:

- ethnography, the understanding of culture
- phenomenology, understanding the true meaning of the object under study
- grounded theory, deriving theory from the data by rigorous data collection and analysis
- case studies (understanding a single unit of study, be it an individual, a theory or a group) and oral biography or narrative analysis (understanding the meaning people give when they talk about the events in their lives).(Grbich 1999; Patton 2002)

In my research, the method I chose (semi-structured interviews) did not stand alone, but was influenced by the theoretical tradition of grounded theory (Glaser & Strauss 1967; Strauss & Corbin 1998). While I had particular research questions I wished to address, I also sought to inductively discover from the data common themes across participants' experience, with collection of data and its analysis occurring in parallel, the one influencing the other. As the qualitative phase was part of an overall mixed methodology, it was beyond the scope of my research to formulate substantive theory as advocated by grounded theory. Thus I was influenced by, but did not attempt to explicitly follow, the tradition of grounded theory as I captured and interpreted what participants had to say about their experience of the CDSMP and their views of supervised exercise.

3.9.4 Data Collection: Semi-structured Interviews

Participant accounts may be in written or verbal form. There is a strong tradition of conducting interviews in qualitative inquiry (Hansen 2006). In addition, much of my clinical work as a physiotherapist involves interviewing patients. Some authors suggest that health professionals may encounter difficulties conducting qualitative interviews (Britten 1997). However, I have observed similarities and differences between qualitative research methods and my approach to conducting a clinical assessment of my patients. (Here, I use the term 'patient' deliberately, as I am referring to my capacity as a healthcare professional.)

The initial part of my clinical interview resembles qualitative research in that I use open-ended questions to help me gain the patients' perspective of issues they face and what is important to them. The second part of the interview centres on medically focused questions and examination, and as such utilises more closed questions. I decided I was well placed to conduct the research interviews due to my experience in using free-flowing conversation while at the same time systematically and comprehensively collecting specific information (Babbie 1999; Frid, Ohlen & Bergbom 2000; Patton 2002; Slaughter et al. 2005).

I saw semi-structured person-to-person interviews as allowing the participants in my study to express their experiences in their own words, enabling me to understand their terminology and perspective of the CDSMP with or without supervised

exercise. At the same time I was able to be sensitive to issues they raised and to pursue these during the interview (Hansen 2006; Patton 2002).

Interviews were conducted so that the retelling of experiences occurred close to the event (Slaughter et al. 2005). It seemed sensible that with a predominantly older age group of people who have a condition such as COPD known to affect memory (Incalzi et al. 2003), that interviews be held within a reasonable time frame after the intervention. The nominated time frame was no more than four weeks after completion of the quantitative study. Interviews commenced on completion of the first CDSMP, and continued in parallel with it until data saturation, as described above, was reached (Patton 2002).

I used a series of open-ended questions to guide the interviews (Table 14), using prompts where necessary (Appendix A.9). The interview questions were formulated to address the research question and to encourage participants to share their experiences. The questions guiding the interview were arrived at in discussion with my supervisors. Open-ended ‘Tell me about . . . ’ questions elicit a rich description of the experience, rather than dichotomous questions that result in a more constrained answer. Every effort was made to avoid two-in-one questions that may be confusing, and questions beginning with ‘Why’, which have the potential to be confronting.

Table 14: Areas of Inquiry Guiding the Interview

Tell me what having a chronic condition means to you.
Tell me about the effect this had on how you think about yourself.
Tell me why you came along to the programme.
Tell me what self-management means to you.
Tell me what exercise means to you.
Tell me what you thought about the programme, with or without supervised exercise.
Tell me your ‘take home’ message.
Tell me what I did not think to ask you. . . .what would you like to add?

To practice the interview schedule and to gain feedback on my style, I conducted a pilot interview with a lady who had been interviewed many times by health professionals and other researchers (Roulston, deMarrais & Lewis 2003). As suggested by others, this pilot interview data was not used in the analysis (Grbich 1999).

In order to gain the participant perspective, I needed to develop rapport as a necessary part of the interview process (Grbich 1999). I had conveyed empathy, concern and a willingness to listen in a non-judgmental respectful way to the participants at the screening appointment and I reinforced this during the programme. However, the face-to-face interviews were more personal and had the potential to be more confronting. As such, I spent some informal time at the beginning of the interview explaining how this research came to take place, and reiterating the value to the research and clinical practice of the participant's perspective concerning exercise, the programme and living with a long term health condition. I again assured confidentiality and anonymity and reassured participants they could stop the interview at any time or decline to discuss a topic should they feel the need to do so. (Only one participant chose to do this when the retelling of some experiences exacted an emotional response.)

I audio recorded the interviews, enabling the interview conversation to flow without distraction from note-taking and also capturing the nuances of the participants' voices, adding a further dimension to the data. I sought verbal permission from the participants to record the interviews. Interviews were recorded using a digital recording device. A digital recorder was chosen to ensure clarity of voice reproduction, unobtrusive ease of operation, and ability to interface directly with a computer. As this equipment was relatively new, I demonstrated it to the participants, and they were shown where to pause or stop the recording if they wished to do so. The recorder was placed on a table, within easy reach and view of the participant.

The recorded interviews commenced by thanking participants for permitting the intrusion into their lives. I explained the purpose of the interview and area of inquiry, emphasising that their feelings and what was important to them, was of greatest interest. Participants' responses led the interviews, with conversational commentary between them and me. On completion of the interview, I thanked participants and asked if they had anything to add, before actually stating that the device was to be turned off. I sent thank-you letters to all participants at the completion of the study (Appendix A.10).

I wrote field notes concerning the setting, rapport and the interviewee's and my own response as soon as possible after the interview. These observations were woven into

the analysis, as a means of contextualising the interview. Issues not initially in the interview framework but raised by more than one participant during interviews were noted, and I followed these up in future interviews (Berg 2004; Hansen 2006).

I listened to the recorded interview as soon as possible after recording, to ensure clarity before transcription. Data was transcribed verbatim. I did not transcribe the data myself, because in addition to studying full-time I continued to work part-time as a physiotherapist. To manage my time efficiently, I was assisted by a nurse who had good transcribing skills and was familiar with people with COPD. I then entered the transcribed texts on a password-protected computer using N-Vivo[®] 2.0 (1999–2000) software, designed specifically for qualitative analysis. N-Vivo[®] software is suited to iterative/thematic analysis, and I used this software as a data management and sorting tool (Hansen 2006). I checked the transcribed data against the recordings for accuracy before proceeding with the data analysis.

3.9.5 Data Analysis

I sought to identify common themes across participants' experiences after attending the CDSMP with or without supervised exercise, as well as their views concerning supervised exercise, while remaining open to and following up other issues participants might raise, or which might be revealed as I analysed the data. As such, I conducted iterative thematic analysis, a common method used in the theoretical traditions of ethnography and grounded theory (Hansen 2006). This inductive approach to my analysis is in sharp contrast to the deductive approach taken in the quantitative arm of the study, wherein I generated hypotheses before data collection began, and subsequently analysed the data according to a statistical framework (Babbie 1999; Patton 2002).

3.9.6 The Steps Followed in the Data Analysis

My iterative thematic analysis was influenced by the work of Tesch (1990) and Morse and Richards (2002). These authors advocate data organising, followed by data interpretation. The text is broken down into smaller units called segments (Tesch 1990) or nodes, with each node being given a name or an identifying code (Morse & Richards 2002). The segments make sense even when taken out of context from the original document, are related to the study purpose and may also suggest

outcomes that the initial research questions had not addressed. These segments are then grouped together and suggest themes that relate to overarching categories. The interpretation may describe common features across texts (descriptive analysis) or relationships between categories with support from within the data (interpretive theory building analysis). Often a combination of the two is used (Tesch 1990). As data analysis progressed, I used a combination of descriptive and thematic analysis. Examples of initial coding and the analysis that led to the development of themes and categories are provided in Appendices B.1, B.2 and B.3.

My analysis incorporated the following steps:

- *An initial reading* of the transcripts to gain a sense of each interview as a whole: ‘What are participants telling me overall about their experience of the CDSMP with or without supervised exercise?’, and, ‘What are they telling me about their lives with COPD?’
- *Coding* and placing the data into nodes or segments, to identify which may be related to the broad research aims: ‘What parts of the interview are related to the research questions as described earlier?’
- *Recoding*, by collapsing nodes into bigger nodes, and by noting segments not related to the initial research aims, and which arose from the interviews: ‘What is the ‘bigger picture’ being described to me?’, and, ‘What other issues of importance have been suggested by the participants?’
- *Identifying emerging themes*: ‘What are the similarities and differences across the interviews?’
- *Categorising* and interpreting the themes, to offer suggestions for future practice and research: ‘What are participants as a group telling us is important to them?’

The study’s credibility was supported by utilising an element of investigator triangulation (Patton 2002). I reviewed the transcripts and discussed the ongoing analysis with two of my supervisors and consensus was reached concerning the categories and themes that emerged. I had informal discussions with the nurse who transcribed the interviews and I recorded insights from these discussions in my field notes, relating them to the participant where possible.

Memos were written in parallel with the above steps, utilising the N-Vivo® 2.0 software and creating links across interviews and with the literature as categories developed.

As the analysis was an iterative process, I will explore the steps followed with reference to the emerging findings which generated additional questions. The findings will be discussed in detail in *Chapter Six*.

3.9.6.1 The Initial Reading

As the purpose of my qualitative research was to identify common themes concerning the impact of COPD, the experience of the CDSMP and supervised exercise and self-management from a participant perspective, my initial reading of the transcripts was directed at gaining a sense of what the participant was telling me concerning these questions. It became obvious to me from the initial reading that participants had suggestions in common for improving the programme. I therefore added another research question, namely, ‘What do people with COPD tell us is important to them with respect to rehabilitation programmes?’

Individuals spoke about the impact of living with COPD in terms of limited activities and an ensuing emotional response. The experience of the CDSMP with or without supervised exercise was one of self-reflection and discovery in terms of developing skills such as action planning and voicing the effect of being with others with a similar condition. I had been sensitised to these themes from my reading of the literature. I was nevertheless interested to hear the participants speaking about the benefit of these processes, thus lending support to the theoretical underpinning of the CDSMP. However, there were some who did not find the experience positive, and this alerted me to the possible negative impact of the programme, and led me to ask ‘Why?’

Self-reflection following attendance at the CDSMP with or without supervised exercise also served to shape a definition of self-management and tasks from a participant point of view. These definitions were also influenced by the experience of the CDSMP. I noticed that participants were mentioning the importance of ‘thinking more about myself’. In addition, self-reflection tempered the response to randomisation. Some participants were pleased they were randomly selected to

participate in the intervention, supervised exercise, and some were not. Some indicated that their views were strengthened or changed following the CDSMP or supervised exercise. I began to ask, 'How is this experience interacting with individuals so that their perceptions are influenced? Why are people indicating they are considering themselves more?' I began to notice recurring comments related to a self-focus. This suggested to me an emerging theme related to an interaction with the CDSMP with or without supervised exercise and a person's view of themselves, one that was not related to the initial research questions.

3.9.6.2 Coding or Segmenting the Data.

As I read the data, I created codes that reflected the research questions, as outlined above. Participants described living with COPD at the time of interview as being one affected by symptoms, difficult emotions, pacing activities, relying on help, changing lifestyle, and limited physical activities. I coded other descriptions given by the participants as 'diagnosis' (delays in diagnosis and communication with health professionals), 'smoking' (their explanation as to the cause of their condition), and hope (with respect COPD prognosis).

3.9.6.3 Recoding

In revisiting the data, I noticed that when describing their lives with COPD participants were indicating they experienced 'losses' accompanied by difficult emotions as well as describing experiences that referred to stigma, both enacted and perceived (Scambler & Hopkins 1986). This was an issue I had not initially sought, and was volunteered by participants in the context of describing their lives with COPD.

Self-management was described in terms of health-related behaviours. Participants included concepts such as 'self-reliance' in their definitions, and I have coded such comments as 'self-referent concepts'.

Reasons for commencing and continuing the programme pointed to motivation. Their continued attendance was also linked with what they saw as being of value in the CDSMP. I observed participants' comments to indicate the benefits of identifying with similar others, social comparison (Buunk et al. 1990; Festinger 1954) and role models (Bandura 1986). These data were recoded as 'social benefits'. Conversation

about exercise revealed to me participants' motivation to exercise as well as the social processes involved.

These data suggested to me an interaction of the CDSMP with self-perception.

The experience of setting action plans caused individuals to focus more on themselves. I have recoded these data, 'self-consideration'. As action plans were realised, individuals' comments suggested a facilitation of self-efficacy, pointing to a code, 'self-regulation'.

Prior attendance at other rehabilitation programmes resulted in comparisons with the CDSMP and supervised exercise, and I have grouped the comments together in a code 'participant engagement' pertaining to either the CDSMP or supervised exercise.

Having hope was mentioned by only two people in this sample. They were both being considered for the same type of surgery. As it appeared to me that this 'promise of things to come' was the source of the hope and was not related to the more general impact of life with COPD or to the CDSMP, I have not pursued this in the data analysis. However, I do recognise that the way people with COPD experience hope would be an area worthy of future investigation.

The initial codes, recoding and relationship to the themes are shown in Appendix B.1. An example of the coding from the transcripts is depicted in Appendix B.2.

3.9.6.4 Emerging Themes

The themes related to the research questions. Participants' descriptions of a life of limited physical activities, ensuing emotional response and experiences of stigma intertwined into one theme — the meaning of COPD for the participants. A second theme related to the strategies these people developed to manage the limitations placed upon their lives by COPD.

Participants spoke of the relevant tasks of self-management to them. Self-referent concepts also emerged from the data, constituting another theme. The impact on self-perception had not been anticipated by me and was an interesting observation, as much of the CDSMP-related literature is related to measurable health outcomes. As I

have mentioned, the sociological literature presents a depth of research with respect to the impact of chronic conditions on the self (Bury 1982, 1991; Charmaz 1983; Charmaz 2002; Hyden 1997; Pound, Gompertz & Ebrahim 1998; Radley & Green 1987; Williams 1984). However, I had not been exposed to this wealth of literature either in my training or clinical work as a physiotherapist. It was not until I began this research that the data from these participants suggested to me that this was an unfolding process, and I found support for this in the sociological literature.

As people spoke about their experiences of the CDSMP, I noticed that the influence of being in a group acted across the experience of the CDSMP and the supervised exercise sessions. The data suggested three themes: common motivational influences for presenting and participating in the programmes, benefits of group participation, and a self-focus. In describing their interactions with the CDSMP, supervised exercise or other rehabilitation programmes, participants indicated their preferences and dislikes, suggesting a final theme of personal engagement.

3.9.6.5 Categorising

I identified three major categories from this data pertaining to the experience and views of people following attendance at the CDSMP±EX. The categories related to:

- Living with COPD
- A Personal Meaning of Self-management
- A Shared Engagement.

I will be presenting these overarching categories and their relationship to the themes which emerged from the data analysis in *Chapter Six, Findings and Outcomes*.

3.10 Chapter Summary

This chapter has provided description of the study design and methodology followed to evaluate the effect of supervised exercise with the CDSMP on physical capacity for people with COPD and to understand the lived experience of the people who took part in this study. A mixed methods approach drew upon the differing but complementary paradigms of quantitative and qualitative research. In this way, it was envisaged that clinical practice would be informed by objective evidence enriched by the lived experiences of participants.

The results of the quantitative outcome measures will be reported in the following chapter, *Chapter Four, Quantitative Research*. The findings of the qualitative enquiry will be presented in *Chapter Five, Qualitative Research*.

4

CHAPTER FOUR: THE QUANTITATIVE RESULTS

4.1 Introduction

This chapter reports the quantitative outcomes of the effect of supervised exercise with the CDSMP. The flow of participants recruited to the study and participant characteristics are presented. Prior to reporting the comparison of the outcomes, the results of data inspection are provided. To determine the effect of supervised exercise with the CDSMP on outcomes for intervention (supervised exercise with the CDSMP) and control groups (CDSMP only); within-group comparisons were made pre and post the intervention. Comparisons were made between the changes in outcomes for each group to establish any differences between groups.

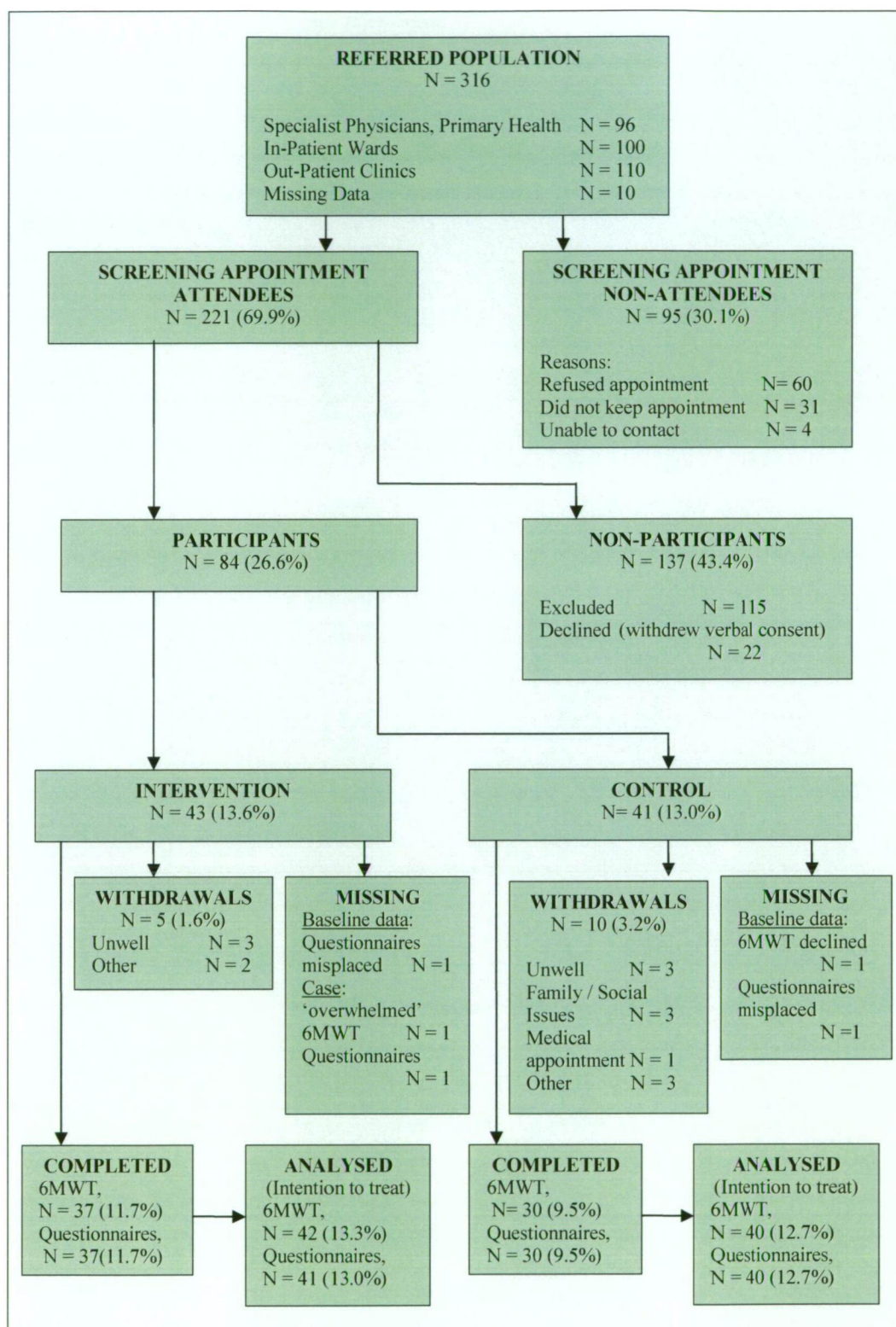
4.2 Results

The results of the quantitative study are reported below.

4.2.1 Participant Flow

During the period January 2005 until March 2007, there were 316 individuals with chronic respiratory conditions who were referred to the physiotherapy outpatient service at a metropolitan tertiary teaching hospital. Figure 2 shows the participant flow during the study.

Figure 2: Participant Flow



Note: Numbers of participants are expressed as raw numbers and as percentages of *total referred population* (n = 316).

Completers are defined as attending at least one CDSMP (with or without supervised exercise) and completing post-data collection.

The study protocol was to recruit participants with a diagnosis of COPD based on spirometry or a physician-confirmed diagnosis. While recognising that spirometry provides the most accurate diagnosis of COPD, this information was not available for a number of patients. Therefore a respiratory specialist-confirmed diagnosis was accepted in order to recruit the number of participants indicated by the power calculations in the time frame for the study.

Of the 221 people screened, 115 people were excluded because of a diagnosis other than COPD, lack of safety to undertake supervised exercise, inability to complete self-administered questionnaires or who did not wish to consent for a variety of reasons reported later in this chapter. Although they could not be included in the study, 24 of those excluded decided to attend the CDSMP. An additional 22 individuals revoked their decision to enrol even though they met all inclusion criteria.

Eighty-four people enrolled in the study, with 43 randomised to the intervention group and 41 to the control group. There were 15 withdrawals (15/84, 17.6 % or 15/316, 4.8 % of those referred). Their reasons for not attending sessions and/or withdrawing are discussed later.

4.2.2 Data Inspection

Data were inspected to detect errors in data entry, missing values and outliers. Data distribution was assessed. The results of these preliminary investigations are presented below. Raw quantitative data is presented in Appendix B.4.

4.2.2.1 Missing Data

Sixty-eight people completed the post-data collection, however missing data resulted in 67 matching data sets for the 6MWT distance and for questionnaires, fulfilling power calculations. As the analysis was by intention to treat, missing variables were replaced by carrying forward the last item measured. For this study, missing post-variables were replaced with the baseline data. Values were not imputed for missing cases. Missing item values were imputed as previously described (*Chapter Three*).

Missing Demographic Data

There were variables missing with respect to the referred population and these data were not available with the referral. Some variables were missing for the participants. Efforts to obtain the data included a retrospective hospital chart audit, access to the existing databases such as the spirometry database, and requests to referring doctors from outside the hospital. Numbers of missing items (failure to record or unavailable) are recorded in the tables below.

Missing Outcomes Data

Variables: Two 6MWTs were not completed at baseline. One participant who was randomised to the intervention group felt ‘overwhelmed’ by the process, subsequently withdrawing permission for data to be used, and was consequently defined as ‘case missing’. Another participant randomised to the control group completed baseline questionnaires and then declined the 6MWT due to increasing breathlessness. Prior to the next session, the participant withdrew from the study without performing the 6MWT, leaving data from 82 people (42 intervention, 40 controls) available for the intention to treat analysis.

Data from three baseline questionnaires were missing: from the participant who felt ‘overwhelmed’ (case missing) and from two others whose questionnaires were misplaced, and were subsequently defined as ‘case missing’. Thus there were 41 baseline questionnaires from the intervention group and 40 from the control group available for the intention to treat analysis.

Items: Items were missing at baseline and post-programme for self-reported exercise, exercise self-efficacy, self-management behaviours, health-related quality of life and stage of change (Table 15). Missing data were few and were completely at random (Fox-Wasylyshyn 2005) except for the baseline data of the exercise self-efficacy scale. Two participants asserted some questions did not pertain to them, and refused to answer questions relating to inconvenience (access to equipment, travelling, closure of the gymnasium) and resistance from others (friends, family, significant others).

Table 15: Missing Data: Items

Missing Items	Self-reported exercise	Self-efficacy	Self-management behaviours	Health-related quality of life	Stage of Change
Baseline	5 (0.02%)	18 (1.2%)	1 (0.08%)	2 (negligible)	1 (0.25%)
Post	0	6 (0.005%)	1 (0.001%)	1 (negligible)	0

Data are reported as number of items and percentage of total items in the measure.

4.2.2.2 Outliers

SPSS statistical software defined outliers at baseline for the 6MWT, for duration and frequency of all and moderate self-reported exercise (CHAMPS questionnaire), for self-management behaviours (Partners in Health scale) and for role physical of the SF-36v2. However, on inspection of the histograms and scatter plots, only the CHAMPS questionnaire data had extreme values. This data had been entered correctly, and it was feasible that the participants concerned would have undertaken the physical activity recorded. It was therefore decided to retain all outliers.

4.2.2.3 Data Distribution and Statistical Tests

Although the baseline 6MWT data for the whole group were slightly negatively skewed, with a skew statistic of -0.893, which is greater than twice the standard error of skew (standard error of skew = 0.266) and Kolmogorov-Smirnoff value of 0.018 (greater than 0.05 suggests normality), other factors suggested little deviation from normality. Inspection of the histogram revealed no long tails, the normal Q-Q probability plot was reasonably straight and the detrended Q-Q plot showed clustering around the zero line with few outliers. Therefore parametric tests were used to compare 6MWT data.

All self-reported exercise data (CHAMPS) were positively skewed. Non-parametric statistical tests were selected to compare differences within and between groups for this variable. Data from other outcome measures were normally distributed and parametric tests were selected for these analyses.

4.2.3 Referred Population and Participant Characteristics

The demographic data of the population referred to the cardiopulmonary outpatients department during the study recruitment, and that of the 84 people who participated in the study are presented in this section.

4.2.3.1 Referred Population

There were 316 older individuals referred in similar proportions from the private sector, hospital wards or clinics to the cardiopulmonary outpatients department. Just under half of the group were female and nearly two-thirds were married. There were more people below the median for socioeconomic status than above (Table 16). Data was not available for education, comorbidities, nationality, or body mass index (BMI).

Spirometry data were unavailable for 194/316 (61%) of people referred. For these individuals, just under one quarter were categorised as having moderate COPD according to the COPD-X guidelines (McKenzie, Frith & Burdon 2003). Equivalent proportions had either severe or mild COPD.

4.2.3.2 Participant Characteristics

Thirty-nine (46.4%) women and 45 (53.6%) men met the study inclusion criteria (Table 16).

Table 16: Referred Population and Participants

Variable		Referred Population N = 316	Study Participants N = 84
Female		152 (48.1%)	39 (46.4%)
Age (years)		66.5 ± 11.7	65.8 ± 9.4
		7 (2.2%) missing	
Not married		114 (39.4%)	34 (40.5%)
Married		175 (60.6%)	50 (59.5%)
		27 missing	
Education:	to year 8	Data not available	21 (25.6%)
	to year 10		37 (45.1%)
	to year 12:		24 (29.3%)
			2 missing
Self-Reported Comorbidities: None		Data not available	61 (73.5%)
Asthma			4 (4.8%)
Cardiovascular			12 (14.5%)
Hypertension			1 (1.2%)
Diabetes			0
Arthritis			1 (1.2%)
Other			4 (4.8%)
			1 missing
Nationality:	Australian	Data not available	78 (94.0%)
	Aboriginal		1 (1.2%)
	Torres Strait Islander		1 (1.2%)
	Other		3 (3.6%)
			1 missing
Referrals:	Private, Primary Health	96 (31.4%)	37 (44.0%)
	Wards	100 (32.7%)	19 (22.6%)
	Clinics	110 (35.9%)	28 (33.4%)
		10 missing	
Socioeconomic Status:	above median	125 (41.7%)	37 (46.2%)
	below median	175 (58.3%)	43 (53.8%)
		16 missing	4 missing
COPD Grade:	Mild (60–80%)	75(38.7%)	20 (29.0%)
	Moderate (40–59%)	47 (24.2%)	16 (23.2%)
	Severe (< 40%)	72 (37.1%)	33 (47.8%)
		122 missing	15 missing
BMI:	Underweight	Data not available	4 (4.8%)
	Healthy weight		22 (27.2%)
	Overweight		18 (21.4%)
	Obese		37 (44.0%)
			3 missing
Mean BMI			29.0 ± 7.07

Note: Data are reported as raw number (per cent) within group status or as means ± standard deviations.

COPD grade is based on per cent of predicted forced expiratory volume in one second. BMI = body mass index.

The majority of participants were older Australians, over half of whom were married, similar to the referred population. The largest proportion had received up to 10 years of education. Only 2284 (26.2%) participants reported the existence of comorbid conditions (mainly cardiovascular disease), capturing the number of coexisting conditions the participant deemed to be relevant. This was not verified by cross-reference to medical records. The majority of participants were referred by respiratory specialists in private practice or by members of a primary healthcare team. The greater proportion was below the median socioeconomic index of advantage and disadvantage. Almost half of the people enrolled suffered from severe COPD. There was wide variability in BMI ranging from 14.9 to 50.4. A BMI of less than 20 is classified as underweight, a healthy range as 20–24.9, overweight as 26–29 and obese as greater than 30 (National Health and Medical Research Council 2008). Just over one-quarter of the group was within the healthy weight range, and over two-thirds were overweight or obese. The greatest proportion was classified as obese, reflected in the mean BMI of 29.0 ± 7.0 .

4.2.4 Comparisons of Baseline Characteristics

Comparisons of baseline characteristics were undertaken to determine any differences between groups. The demographic variables analysed were age, gender, marital status, socioeconomic status, referral source, and COPD grade. These analyses are presented below.

Initial comparisons of demographic data were performed to determine if there was any bias with respect to people not participating in the study:

- screening appointment attendees versus non-attendees (Table 17)
- study participants versus non-participants (Table 18)
- completers versus withdrawals (Table 19).

Additional demographic baseline comparisons were made between:

- study participants versus the balance of referrals, to determine generalisability of results (Appendix 9)
- intervention group versus controls, to determine the effectiveness of randomisation (Table 20)

- outcomes were also compared at baseline between intervention and control groups (Table 21).

4.2.4.1 Screening Appointment: Attendees versus Non-Attendees

The differences between the groups for gender, age, marital status, socioeconomic status and severity of COPD were small and there were no significant differences between the 221 attendees and the 95 non-attendees. The mean of the attendees' age was two years older than non-attendees. Available data showed almost equal proportions of people with mild COPD as with severe COPD attended, whereas those with mild COPD formed almost half the group of non-attendees. The majority of both groups were below the median for the socioeconomic index for advantage and disadvantage. People referred from the wards were least likely, whereas those referred from the private sector were most likely, to attend an appointment, the differences being significant ($p < 0.001$) (Table 17).

Table 17: Screening Appointment Attendees versus Non-Attendees

Variable	Referred Population N = 316	Attendees N = 221	Non- attendees N = 95	p value A versus Non-A
Female	152 (48.1%)	104(47.1%)	48 (50.5%)	0.658
Age (years)	66.5 ± 11.65 7 missing	67.1 ± 11.04	65.0 ± 12.98	0.150
Not married	114 (39.4%)	77 (37.4%)	37 (44.6%)	0.317
Married	175 (60.6%)	129 (62.6%)	46 (55.4%)	
	27 missing	15 missing	12 missing	
Referrals: Primary Health,	96 (31.4%)	79(36.9%)	17 (18.5%)	0.000
Private	100 (32.7%)	54 (25.2%)	46 (50.0%)	
Wards	110 (35.9%)	81 (37.9%)	29 (31.5%)	
Clinics	10 missing	7 missing	3 missing	
Socioeconomic Status: above median	125 (41.7%)	90 (42.7%)	35 (39.3%)	0.685
below median	175 (58.3%)	121 (57.3%)	54 (60.7%)	
	16 missing	10 missing	6 missing	
COPD Grade:				0.467
Mild (60–80%)	75(38.7%)	54 (36.7%)	21 (44.7%)	
Moderate (40–59%)	47 (24.2%)	35 (23.8%)	12 (25.5%)	
Severe (< 40%)	72 (37.1%)	58 (39.5%)	14 (29.8%)	
	122 missing	74 missing	48 missing	

Note: Data are reported as either raw number (percent) within study group status and as means ± standard deviations.
The p-values are from t tests or chi-square analyses. A = attendees, Non-A = non-attendees.

4.2.4.2 Participants versus Non-Participants

Of the 221 screened, 137 did not participate in the study and their demographics are compared with study participants in Table 18. Participants were older, a greater proportion was referred by healthcare providers in private practice and nearly half of the group had severe COPD. Ward and clinic referrals accounted for two-thirds of the referral source for non-participants, the majority of whom had mild COPD. The differences between the groups were not statistically significant.

Table 18: Participants versus Non-participants

Variable	Participants N = 84	Non-Participants N = 137	p value
Female	39 (46.4%)	65 (47.4%)	1.00
Age (years)	65.8 ± 9.35	68.1 ± 11.90	0.131
		2 missing	
Not married	34 (40.5%)	43 (35.2%)	0.538
Married	50 (59.5%)	79 (64.8%)	
		15 missing	
Referral Source: Primary Health, Private	37 (44.0%)	42 (32.3%)	0.220
Wards	19 (22.6%)	35 (26.9%)	
Clinics	28 (33.4%)	53 (40.8%)	
		7 missing	
Socioeconomic Status: above median	37 (46.2%)	53 (40.5%)	0.495
below median	43 (53.8%)	78 (59.5%)	
	4 missing	6 missing	
COPD Grade: Mild (60–80%)	20 (29.0%)	34 (43.6%)	0.108
Moderate (40–59%)	16 (23.2%)	19 (24.4%)	
Severe (< 40%)	33 (47.8%)	25 (32.0%)	
	15 missing	59 missing	

Note: Data are reported as either raw number (per cent) within study group status and as means ± standard deviations. The p-values are from t tests or chi-square analyses.

The baseline data of the participants (n = 84) were also compared with the balance of the referred population (n = 316 - 84 = 232) and confirmed the previous analyses, showing no statistically significant differences except for referral source (p = 0.008). (Appendix B.4.)

4.2.4.3 Completers versus Withdrawals

An inspection of the baseline characteristics of those completing the study versus withdrawals was performed to ascertain any baseline differences between these groups (Table 19).

Table 19: Completers versus Withdrawals

Variable		Participants N = 84	Completers N = 68	Withdrawals N = 15 1 missing	p value C versus WD
Female		39 (46.4%)	31 (45.6%)	8 (53.3%)	0.408
Age (years)		65.8 ± 9.35	66.3 ± 8.69 N = 70	63.5 ± 12.04 N = 14	0.298
Not married		34 (40.5%)	28 (41.2%)	5 (33.3%)	Not reported
Married		50 (59.5%)	40 (58.8%)	10 (66.7%)	
Education:	to year 8	21 (25.6%)	19 (28.4%)	2 (13.3%)	Not reported
	to year 10	37 (45.1%)	31 (46.3%)	6 (40.0%)	
	to year 12	24 (29.3%)	17 (25.4%)	7 (46.7%)	
		2 missing	1 missing		
Referrals:	Primary Health, Private	37 (44.0%)	30 (44.1%)	7 (46.7%)	0.543
	Wards	19 (22.6%)	17 (25.0%)	2 (13.3%)	
	Clinics	28 (33.3%)	21 (30.9%)	6 (40.0 %)	
Socioeconomic Status:	above median	37 (46.3%)	29 (44.6%)	8 (53.3%)	0.747
	below median	43 (53.8%)	36 (55.4%)	7 (46.7%)	
		4 missing	3 missing		
COPD Grade:					
	Mild (60–80%)	20 (29.0%)	17 (29.3%)	3 (27.3%)	Not reported
	Moderate (40–59%)	16 (23.2%)	13 (22.4%)	3 (27.3%)	
	Severe (< 40%)	33 (47.8%)	28 (48.3%)	5 (45.4%)	
		15 missing	10 missing	4 missing	

Note: Data are reported as either raw number (per cent) within study group status and as means ± standard deviations. The p-values are from t tests or chi-square analyses. C = completers, WD = withdrawals.

The participant who felt ‘overwhelmed’ was deemed as ‘missing’ and not a ‘withdrawal’, because they did complete the programme. Those whose data was misplaced were not seen as withdrawals for this analysis, as they also completed the programme.

Completers were defined as those attending at least one CDSMP session and both of the data collection sessions. Completers were older; fewer were married and were less likely to have been educated beyond Year 10. Twice the proportion of completers was referred from the wards, compared with those who withdrew, and

more completers were below the median of socioeconomic status than above. None of these differences reached statistical significance, although p-values could not be reported for marital status and education. There were comparable proportions with respect to severity of COPD, but data in the categories were insufficient for statistical analysis.

4.2.4.4 Intervention versus Control Groups

Demographic comparisons are shown in Table 20. The groups did not differ significantly on any measure, suggesting randomisation was effective. However, the intervention group were a mean 2.6 years younger, had fewer educated to Year 12 (23.8% versus 35% of the control group), had fewer comorbidities and had a greater percentage with moderate or severe COPD. As there were insufficient data for the category of nationality, p-values are not reported. Comorbidity categories were collapsed into two larger categories.

Baseline outcome variables were compared to ascertain any differences between groups at baseline (Table 21). As there were a large number of comparisons for secondary measures, the level of significance for secondary outcomes was recalculated at $p = 0.003$, using a Bonferroni adjustment (Pallant 2005). There were no statistically significant differences between groups. However, data from the CHAMPS physical activity questionnaire suggest the control group were active more frequently and for 4 hours more per week than the intervention group. Conversely, a greater proportion of people in the intervention group responded that they met recommended exercise criteria, suggesting they undertook more moderate exercise than the control group.

Table 20: Intervention versus Control Group: Demographic Data

Variable		Participants N = 84	Intervention (CDSMP+Ex) N = 43	Control (CDSMP- Only) N = 41	p value I versus C
Female		39 (46.4%)	20 (46.5%)	19 (46.3%)	0.988
Age (years)		65.8 ± 9.35	64.5 ± 9.13	67.1 ± 9.41	0.193
Not married		34 (40.5%)	18 (41.9%)	16 (39.0%)	0.966
Married		50 (59.5%)	25 (58.1%)	25 (61.0%)	
Education:	to year 8	21 (25.6%)	12 (28.6%)	9 (22.5%)	0.525
	to year 10	37 (45.1%)	20 (47.6%)	17 (42.5%)	
	to year 12	24 (29.3%)	10 (23.8%)	14 (35.0%)	
	2 missing		1 missing	1 missing	
Self-Reported Co morbidities:		61 (73.5%)	34 (79.1%)	27 (67.5%)	Not reported
None					
Asthma		4 (4.8%)	1 (2.3%)	3 (7.5%)	
Cardiovascular		12 (14.5%)	6 (14.0%)	6 (15.0%)	
Hypertension		1 (1.2%)	0	1 (2.5%)	
Diabetes		0	0	0	
Arthritis		1 (1.2%)	0	1 (2.5%)	
Other		4 (4.8%)	2 (4.6%)	2 (5.0%)	
1 missing				1 missing	
Self-Reported Co morbidities: None		61 (72.6%)	34 (79.1)	27 (67.5%)	0.345
Co morbidity		22 (26.2%)	9 (20.9%)	13 (32.5%)	
1 missing				1 missing	
Nationality:	Australian	78 (94.0%)	40 (95.2%)	38 (92.7%)	Not reported
	Aboriginal	1 (1.2%)	1 (2.4%)	0	
	Torres Strait Islander	1 (1.2%)	1 (2.4%)	0	
	Other	3 (3.6%)	0	3 (7.3%)	
1 missing			1 missing		
Referrals: Primary Health, Private		37 (44.0%)	18 (41.9%)	19 (46.3%)	0.797
Wards		19 (22.6%)	11 (25.6%)	8 (19.5%)	
Clinics		28 (33.3%)	14 (32.6%)	14 (34.2%)	
Socioeconomic Status:					1.000
above median		37 (46.3%)	19 (47.5%)	18 (45.0%)	
below median		43 (53.8%)	21 (52.5%)	22 (55.0%)	
4 missing			3 missing	1 missing	
COPD Grade: Mild (60–80%)		20 (29.0%)	8 (21.6%)	12 (37.5%)	0.226
Moderate (40–59%)		16 (23.2%)	11 (29.7%)	5 (15.6%)	
Severe (< 40%)		33 (47.8%)	18 (48.6%)	15 (46.9%)	
15 missing			6 missing	9 missing	
BMI		29.0 ± 7.07	28.4 ± 7.63	29.7 ± 6.50	0.436
3 missing			2 missing	1 missing	

Note: Data are reported as either raw number (percent) within study group status and as means ± standard deviations. The p-values are from t-tests or chi-square analyses. I = intervention, C = control.

Table 21: Intervention and Control Group: Baseline Outcome Variables

Variable	Intervention (CDSMP+Ex)	Control (CDSMP-Only)	p value
Primary Outcome	(n = 42)	(n = 40)	
6MWD (metres)	351.6 ± 122.9	353.0 ± 97.4	.953
Secondary Outcomes	(n = 41)	(n = 40)	
All exercise: duration (hours per week)	5.250 (0.00—26.00)	9.250 (0—52.25)	0.011
All exercise: frequency (times per week)	9.0 (0.0—49.0)	13.5 (0.0—59.0)	0.126
Moderate exercise: duration (hours)	0.500 (0.00—19.50)	1.500 (0.00 -10.25)	0.171
Moderate exercise: frequency (times per week)	2.0 (0 -20.0)	2.0 (0.0—23.0)	0.491
Exercise self-efficacy (scale 0–5)	2.7 ± 1.1	2.8 ± 1.0	0.763
Self-management behaviours (scale 0–8)	6.1 ± 1.1	6.2 ± 1.0	0.492
Shortness of breath: Severity (centimetres)	7.1 ± 2.3	6.8 ± 2.4	0.592
Shortness of breath: Frequency (centimetres)	6.9 ± 2.6	6.4 ± 2.6	0.330
SF-36v2 Physical Function	29.26 ± 8.99	28.99 ± 8.04	0.886
SF-36v2 Role Physical	31.95 ± 10.37	32.12 ± 9.42	0.938
SF-36v2 Bodily pain	45.64 ± 11.68	45.09 ± 11.49	0.832
SF-36v2 General Health	30.30 ± 9.88	32.41 ± 8.96	0.317
SF-36v2 Vitality	41.74 ± 9.19	40.77 ± 9.69	0.648
SF-36v2 Social Function	42.75 ± 13.19	39.94 ± 11.37	0.309
SF-36v2 Role Emotional	36.25 ± 16.10	37.22 ± 15.28	0.782
SF-36v2 Mental Health	47.67 ± 11.66	46.21 ± 10.68	0.557
SF-36v2 Physical Component Summary	31.53 ± 8.19	31.97 ± 7.247	0.796
SF-36v2 Mental Health Component Summary	46.74 ± 12.85	45.53 ± 12.17	0.664
Achieving Exercise Criteria: Yes	11 (26.8%)	6 (15.0%)	0.301
No	30 (73.2%)	34 (85.0%)	
Stage of Change for Exercise: Precontemplation	4 (9.8%)	6 (15.0%)	0.789
Contemplation	14 (34.1%)	17 (42.5%)	
Preparation	9 (22.0%)	7(17.5%)	
Action	6 (14.6%)	5(12.5%)	
Maintenance	8 (19.5%)	5(12.5%)	

Note: Data are reported as either raw number (percent) within study group status, as mean ± standard deviation. The p-values are from t-tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment. I = intervention, C = control.

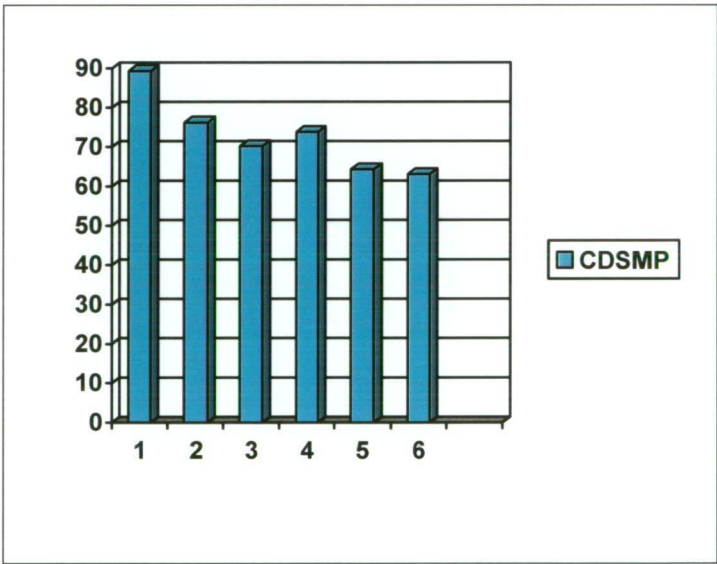
4.2.5 Exploratory Data Analyses

Additional analyses explored attendance rates and reasons for non-attendance and attrition from the programmes. These are reported below.

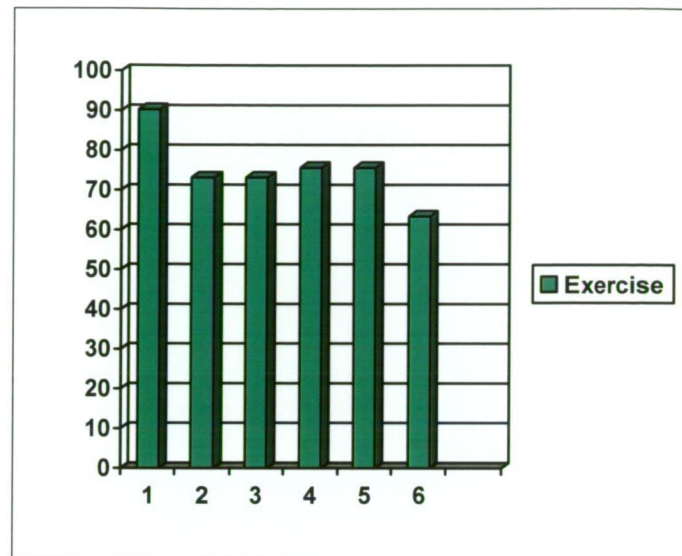
4.2.5.1 Attendance Rates

The proportions of participants attending the CDSMP or exercise sessions are graphically depicted in Figures 3 and 4 below. Participants attended a median of five sessions for the CDSMP and supervised exercise. Over one-third who enrolled attended all of the six sessions of the CDSMP (33/84, 39.3%) or supervised exercise (14/41, 34.15%). Over 60% of participants attended the CDSMP or exercise sessions on any one occasion. There was a gradual decrease in attendances over the duration of the programme.

Figure 3: Attendances at CDSMP Sessions (n = 84)



Legend: 1, 2, 3, 4, 5, 6 = 1st, 2nd, 3rd, 4th, 5th, 6th CDSMP session.
Y-axis = Percentage of participants attending each session.

Figure 4: Attendances at Exercise Sessions (n = 41)

Legend: 1, 2, 3, 4, 5, 6 = 1st, 2nd, 3rd, 4th, 5th, 6th supervised exercise session.
Y-axis = Percentage of participants attending each session.

4.2.5.2 Reasons for Attrition

Reasons for not making or keeping appointments, declining study participation or withdrawing were varied. Eighteen initial categories were collapsed into eight larger categories to increase the numbers in the cells for chi-square analysis. Table 22 illustrates the reasons and the final categories they formed.

Table 22: Reasons for Non-Attendance or Non-participation

Reasons	Final Category
Unwell	Unwell
Medical appointment	Other commitment
Other appointment	
Holidays	
Work	
Family/social commitments	
Travel cost/distance	Travel
Not a group person	Not suitable
Exercise at home	
Did not wish to commit	
Not interested	
No reason	
Attended other programme	Attended other programme
Participating in other research project	
Unable to contact	Unable to contact
Did not meet inclusion criteria and did not enrol in programme	Did not meet inclusion criteria
Did not meet inclusion criteria and enrolled in programme	
Other	other

4.2.5.3 Reasons for Non-attendance or Non-participation

While the actual reasons people gave were similar across the groups for non-attendance at the screening appointment or for non-participation in the study, the proportions of people between the groups proffering the reason differed significantly ($p < 0.001$) (Figure 5).

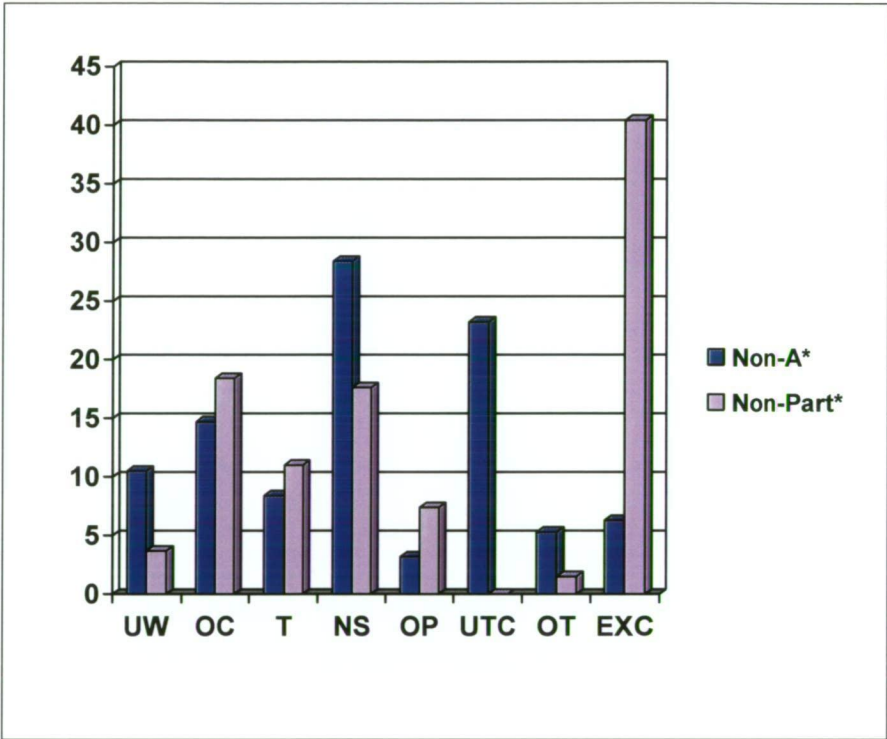
Of the non-attendees at the screening appointment, 23.2% were unable to be contacted to ascertain a reason for their non-attendance. Reasons were not recorded for one study non-participant, leaving data from 136 people available for analysis in that group.

Apart from those excluded due to not meeting inclusion criteria, other than verbal consent, the main reason given for not attending the screening appointment or for not consenting to participate in the study was programme unsuitability (22.1%).

However, non-attendees compared with non-participants were more likely to cite 'not suitable' (28.4% versus 17.6%) and to 'being unwell' (10.5% versus 3.7%). The

latter were more likely to have other commitments preventing them from enrolling in the programme (18.4% versus 10.5%). In addition, they were twice as likely to have attended another programme previously, although these numbers were small (7.4% versus 3.2%).

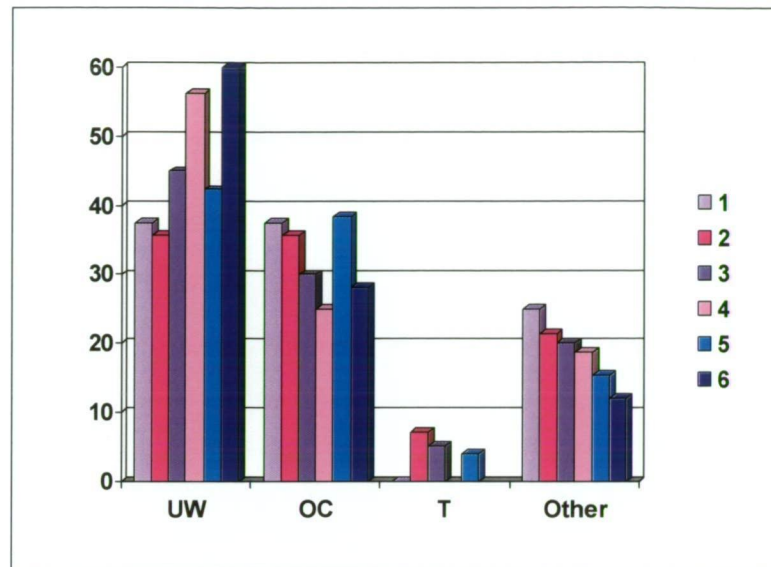
Figure 5: Reasons for Non-attendance (n = 95) or Non-participation (n = 136)



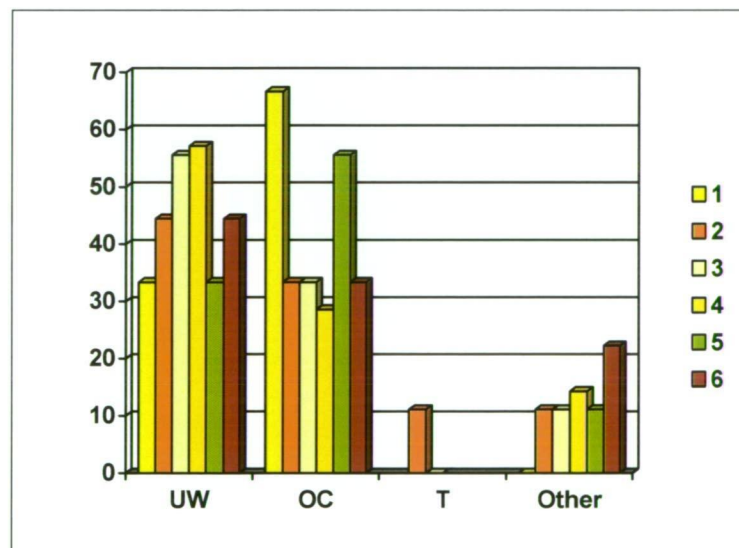
Legend: UW = unwell, OC = other commitment, T = transport, NS = not suitable, OP = attended other programme, UTC = appointment made, unable to contact to ascertain reason for non-attendance, EXC = excluded, did not meet inclusion criteria, OT = other reason. Non-A = Non-attendance at screening appointment, Non-Part = Non-participant in study. Y-axis: percentage within each category. The p-values are from chi-square analyses with the level of significance $p < 0.05$. * $P < 0.001$ for comparisons between categories for Non-attendees and for Non-Participants.

4.2.5.4 Reasons for Non-attendance at CDSMP or Supervised Exercise Sessions

Figures 6 and 7 show the reasons for non-attendance at the CDSMP or supervised exercise sessions. Across the six CDSMP and supervised exercise sessions, being unwell was the most frequently cited reason for missing a session. Transport difficulties or distance to travel were not a major barrier to attendance at the CDSMP or supervised exercise sessions, and was only cited for three of the CDSMP sessions and one of the supervised exercise sessions.

Figure 6: Reasons for Non-attendance at CDSMP sessions (n = 84)

Legend: UW = unwell, OC = other commitment, T = transport, O = other. 1, 2, 3, 4, 5, 6 = 1st, 2nd, 3rd, 4th, 5th, 6th CDSMP session. Y-axis: Percentage within each category.

Figure 7: Reasons for Non-attendance at Exercise Sessions (n = 43)

Legend: UW = unwell, OC = other commitment, T = transport, O = other. 1, 2, 3, 4, 5, 6 = 1st, 2nd, 3rd, 4th, 5th, 6th supervised exercise session. Y-axis: Percentage within each category.

4.2.6 Comparisons: Intervention and Control Groups

Comparisons were made between pre and post intervention measures for the active and control groups to investigate any within-group changes. The pre and post differences for outcomes for the intervention and control groups were compared to determine any between-group changes (Tables 23–25).

4.2.6.1 Primary Outcome: 6-Minute Walk Test

The distances walked in the 6MWT varied substantially, evidenced by the large standard deviations for intervention and control groups (Table 23). This is consistent with the variable impact of COPD on individuals. Both groups significantly increased the distance walked following attendance at the CDSMP with or without supervised exercise. However, the mean change between the groups was small (18.6 versus 20.0 metres) and was not statistically significant. A learning effect is possible but as the tests were conducted at least one week apart, the possibility is reduced. The majority of participants (78.5% intervention and 77.5% control) did not reach the acknowledged minimal clinical important difference (MCID) of 54 metres (95% confidence interval of 37–71 metres) for distance walked (Redelmeier et al. 1997). The whole study group walked a mean distance of 352.3 ± 110.5 metres following the CDSMP with or without supervised exercise, with a mean change of 19.3 ± 48.1 metres.

Table 23: Primary and Secondary Outcomes

Variable	CDSMP+Ex (Intervention)			CDSMP-Only (Control)			Change		
	Baseline	Post	p value	Baseline	Post	p value	CDSMP+Ex	CDSMP-only	p value
Primary Outcome	N = 42	N = 42		N = 40	N = 40				
6MWT distance (metres)	351.6 ± 122.9	370.2 ± 128.2	0.000	353.0 ± 97.4	373.0 ± 97.7	0.000	18.6 ± 46.2	20.0 ± 50.6	0.901
Secondary Outcomes	N = 41	N = 41		N = 40	N = 40				
All exercise: duration (hours per week)	5.250 (0.00–26.00)	6.750 (0.00–36.50)	0.004	9.250 (0–52.25)	8.500 (0–31.75)	0.455	2.250 (-12.25–18.00)	- 0.125 (-52.25–15.00)	0.067
All exercise: frequency (times per week)	9.0 (0.0–49.0)	19.0 (0.0–115.0)	0.001	13.5 (0.0–59.0)	14.0 (0.0–50.0)	0.526	6.0 (-12.0–115.0)	1.0 (-59.0–22.0)	0.118
Moderate exercise: duration (hours)	0.500 (0.00–19.50)	1.750 (0.00–30.75)	0.002	1.500 (0.00–10.25)	1.375 (0.00–15.75)	0.345	1.000 (-5.75–14.00)	0.000 (-9.75–10.25)	0.230
Moderate exercise: frequency (times)	2.0 (0–20.0)	3.0 (0.0–22.0)	0.007	2.0 (0.0–23.0)	3.0 (0–22.0)	0.290	1.0 (-8.0–11.0)	0.5 (-23.0–16.0)	0.766
Exercise self-efficacy (Scale 0-5)	2.7 ± 1.1	2.9 ± 1.1	0.354	2.8 ± 1.0	3.0 ± 1.0	0.290	0.2 ± 1.1	0.2 ± 1.1	0.892
Self-management behaviours (Scale 0-8)	6.1 ± 1.1	6.3 ± 0.8	.037	6.2 ± 1.0	6.4 ± 1.0	0.076	0.3 ± 0.8	0.2 ± 0.7	0.698

Note: Data are reported as either raw number (percentage) within study group status, as mean ± standard deviation. The p-values are from t tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment.

Table 24: Secondary Outcomes

Variable	CDSMP+Ex (Intervention)			CDSMP-Only (Control)			Change		
	Baseline	Post	p value	Baseline	Post	p value	CDSMP+Ex	CDSMP-only	p value
Secondary Outcomes	N = 41	N = 41		N = 40	N = 40				
Shortness of breath: severity (cms)	7.1 ± 2.3	6.3 ± 2.5	.032	6.8 ± 2.4	6.8 ± 2.3	0.989	- 0.8 ± 2.4	0.0 ± 2.3	0.118
Shortness of breath: frequency (cms)	6.9 ± 2.6	6.3 ± 2.7	0.128	6.4 ± 2.6	6.5 ± 2.5	0.700	- 0.6 ± 2.7	0.1 ± 2.1	0.151
Exercise Criteria: Yes	11 (26.8%)	22 (53.7%)	0.066	6 (15.0%)	18 (45.0%)	0.013	Regressed: 2 (4.9%)	0	No report
No	30 (73.2%)	19 (46.3%)		34 (85.0%)	22 (55.0%)		No change, criteria not achieved: 17 (41.4%) No change, criteria achieved: 9 (22.0%) Progressed: 13 (31.7%)	22 (55.0%) 6 (15.0%) 12 (30.0%)	
Stage of Change:									No report
Precontemplation	4 (9.8%)	3 (7.3%)	No report	6 (15.0%)	4 (10.0%)	No report	Not reported	Not reported	No report
Contemplation	14 (34.1%)	10 (24.4%)		17 (42.5%)	13 (32.5%)				
Preparation	9 (22.0%)	4 (9.8%)		7 (17.5%)	6 (15.0%)				
Action	6 (14.6%)	15 (36.6%)		5 (12.5%)	9 (22.5%)				
Maintenance	8 (19.5%)	9 (22.0%)		5 (12.5%)	8 (20.0%)				
Recode Stage of Change:									
Intending	27 (65.9%)	17 (41.5%)	0.123	30 (75.0%)	23 (57.5%)	No report	Regressed: 2 (4.9%)	1 (2.5%)	No report
Acting	14 (34.1%)	24 (58.5%)		10 (25.0%)	17 (42.5%)		No change, intending: 15 (36.6%) No change, acting: 11 (26.8%) Progressed: 13 (31.7%)	22 (55.0%) 8 (20.0%) 9 (22.5%)	

Note: Data are reported as either raw number (percentage) within study group status, as mean ± standard deviation. The p-values are from t tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment.

Table 25: Secondary Outcomes

Variable	CDSMP+Ex (Intervention)			CDSMP-Only (Control)			Change		
	Baseline (n = 41)	Post (n = 41)	p value	Baseline (n = 40)	Post (n = 40)	p value	CDSMP+Ex	CDSMP-Only	p value
Secondary Outcomes: SF-36v2									
Physical Function	29.26 ± 8.99	30.74 ± 9.04	0.076	28.99 ± 8.04	30.41 ± 8.17	0.254	1.49 ± 5.20	1.42 ± 7.78	0.963
Role Physical	31.95 ± 10.37	34.33 ± 10.25	0.033	32.12 ± 9.42	35.05 ± 9.81	0.038	2.38 ± 6.92	2.93 ± 8.65	0.752
Bodily pain	45.64 ± 11.68	47.71 ± 10.99	0.206	45.09 ± 11.49	44.46 ± 11.48	0.621	2.07 ± 10.32	-0.62 ± 7.90	0.191
General Health	30.30 ± 9.88	31.24 ± 8.57	0.467	32.41 ± 8.96	31.81 ± 10.08	0.580	0.94 ± 8.21	-0.60 ± 6.79	0.361
Vitality	41.74 ± 9.19	42.95 ± 8.95	0.382	40.77 ± 9.69	43.74 ± 8.07	0.032	1.22 ± 8.83	2.97 ± 8.45	0.366
Social Function	42.75 ± 13.19	43.28 ± 10.92	0.777	39.94 ± 11.37	43.21 ± 11.05	0.050	0.53 ± 11.94	3.27 ± 10.24	0.271
Role Emotional	36.25 ± 16.10	37.96 ± 15.81	0.282	37.22 ± 15.28	39.07 ± 13.71	0.358	1.71 ± 10.03	2.85 ± 12.54	0.956
Mental Health	47.67 ± 11.66	47.85 ± 10.04	0.849	46.21 ± 10.68	47.46 ± 10.11	0.428	0.19 ± 6.44	1.26 ± 9.92	0.567
Physical Component Summary	31.53 ± 8.19	33.54 ± 7.27	0.026	31.97 ± 7.24	32.68 ± 8.40	0.506	2.00 ± 5.56	0.70 ± 6.64	0.340
Mental Component Summary	46.74 ± 12.85	47.16 ± 11.25	0.707	45.53 ± 12.17	47.90 ± 10.41	0.205	0.42 ± 7.09	2.38 ± 11.65	0.362

Note: Data are reported as either raw number (percent) within study group status, as mean ± standard deviation. The p-values are from t-tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment.

Variance in 6-Minute Walk Test Distance

The associations between the change in 6MWT distance and the selected variables were weak, with all Pearson's correlation coefficients being less than 0.3 (Table 26). Frequency of moderate exercise, education and exercise self-efficacy showed the strongest correlations.

Table 26: Variables associated with change in 6-Minute Walk Test distance (metres)

Variable	Pearson Correlation <i>r</i> (significance)	Unstandardised Coefficient, B (95% confidence interval)
1. Study allocation	-0.044 (0.359)	-4.6 (-30.0, 20.8)
2. Age	-0.123 (0.160)	-0.7 (-2.2, 0.7)
3. Gender (female)	-0.042 (0.367)	-4.3 (-21.0, 29.7)
4. Education: year 8 and below	-0.220 (0.037)	Reference
year 10 and below	0.099 (0.214)	-24.2 (-53.8, 5.1)
year 12 and below		-4.1 (-38.1, 29.9)
5. Breathlessness		
Perceived shortness of breath: severity	-0.083 (0.255)	-1.8 (-7.2, 3.6)
Perceived shortness of breath: frequency	-0.023 (0.429)	-0.5 (-5.5, 4.6)
6. Exercise:		
Duration of all exercise	0.001 (0.497)	0.006 (-1.9, 1.9)
Frequency of all exercise	-0.091 (0.233)	-0.5 (-1.7, 0.8)
Duration of moderate exercise	-0.057 (0.324)	0.3 (-5.1, 5.8)
Frequency of moderate exercise	-0.188 (0.066)	-2.0 (-4.6, 0.6)
Exercise participation (yes)	0.051 (0.342)	6.5 (-25.2, 38.1)
Physical component summary	0.024 (0.424)	0.2 (-1.5, 1.8)
7. Mental component summary	-0.063 (0.306)	-0.3 (-1.3, 0.8)
8. Self-efficacy	0.140 (0.132)	7.0 (-5.8, 19.0)
9. Body Mass Index	-0.003 (0.491)	-0.021 (-1.82, 1.78)

As noted earlier, although statistical significance was not reached, the control group were older, had more people educated to Year 12, had more with mild COPD and had a higher level of self-reported exercise at baseline than the intervention group. To investigate whether the lack of significant difference in the change between the groups had been masked by a possible imbalance between the groups, linear regression analyses of association of study allocation plus selected variables on

change in 6MWT distance was performed. Severity and frequency of breathlessness were selected rather than COPD grade as the latter had missing data (Table 27).

Table 27: Association of study allocation plus selected variables on change in 6-Minute Walk Test distance (metres)

Variable	Study Allocation Unstandardised Coefficient, B	95% Confidence Interval	10% Change in B
1. Study allocation (Intervention)	-4.61	-30.04, 20.83	Reference
2. Study allocation + age	-7.30	-33.19, 18.58	Yes
3. Study allocation + gender (female)	-4.71	-30.33, 21.91	No
4. Study allocation + education	-8.36	-33.62, 16.89	Yes
5. Breathlessness			
Study allocation + shortness of breath, severity	-2.20	-28.37, 23.97	Yes
Study allocation + shortness of breath: frequency	-2.24	-28.61, 24.13	Yes
6. Exercise			
Study allocation + duration of all exercise	-2.60	-29.79, 24.59	Yes
Study allocation + frequency of all exercise	-2.46	-28.60, 23.68	Yes
Study allocation + duration of moderate exercise	-2.39	-28.60, 23.82	Yes
Study allocation + frequency of moderate exercise	-1.04	-26.89, 24.82	Yes
Study allocation + exercise participation (yes)	-4.03	-31.09, 23.04	Yes
Study allocation + physical component summary	-2.54	-28.85, 23.70	Yes
7. Study allocation + mental component summary	-2.17	-28.39, 24.06	Yes
8. Study allocation + self-efficacy	-3.17	-29.19, 22.85	Yes
9. Study allocation + body mass index	-0.044	-1.87, 1.78	No

Note: From each group, retain factor most strongly associated with reference variable and if effect is greater than or equal to 10% = 0.5 metres and/or plausible biological grounds to retain.

After adjusting for age and education, there was more of a difference between the groups, with the intervention group showing less of an increase in distance walked. Adjusting for baseline self-reported exercise levels decreased the difference between the two groups. However, adjusting did not alter the results showing that the change in distance walked was less for the intervention group than the control group. Therefore, there was no reason to doubt the results of the unadjusted analysis.

Having ascertained that there was no confounding of the results, a multivariable analysis was performed to establish which variables best predict the change in 6MWT distance and so yield information as to why the change in 6MWT distance did not reach clinical significance. As the sample was small, the effect on change in 6MWT distance was the criteria for including variables in a multivariable regression model, rather than a p-value of 0.2 (Bowers 2002).

The intervention group walked 4.61 metres less than the control group when available data was entered in a linear regression for study allocation (Table 27). A 10% change in this distance is equivalent to 0.5 metres; that is a distance less than 4.15 metres or greater than 5.07 metres. The variable with the greatest influence on the change in distance walked from each group of similar variables was retained for the multivariable analysis. The multivariable regression model was built, following a backwards stepwise elimination process (Bowers 2002). Values reaching statistical significance were retained, then the variable with the largest p-value was removed first, commencing with study allocation. The final model retained frequency of moderate self-reported exercise and exercise self-efficacy as the independent variables with the post- programme 6MWT distance the dependent variable (Table 28).

The removal of self-efficacy from the model did not improve the goodness of fit as determined by the adjusted R^2 which changed from 0.050 to 0.020.

Table 28: Association of selected variables on change in 6-Minute Walk Test distance (metres)

Variable	Unstandardised Coefficient, B	Standardised Coefficient, Beta	95% confidence interval for B	Significance
Frequency of moderate exercise	-2.70	-0.257	-5.37, -0.025	0.048
Self-efficacy	11.03	0.220	-1.715, 23.779	0.089

Note: $R^2 = 0.079$, adjusted $R^2 = 0.050$ ANOVA = 0.075

4.2.8.2 Secondary Outcomes

There were 20 end-points for secondary outcomes (Tables 23-25), necessitating the application of a Bonferroni adjustment of the p-value to avoid committing a Type I error (Pallant 2005). This resulted in an adjusted $p < 0.003$.

Self-reported Exercise

Following attendance at the CDSMP with supervised exercise, the intervention group were engaged in all exercise six times more per week than at baseline, and increased the duration of moderate intensity reported exercise by one hour per week. These changes reached statistical significance. There were non-significant increases in the other two domains of self-reported exercise. The control group showed a slight decrease in duration of all exercise, no change in moderate self-reported exercise but a slight increase in frequency. These changes did not reach statistical significance. Similarly, the changes in self-reported exercise between the groups were not significant (Table 23).

Exercise Self-efficacy

There were no statistically significant changes in exercise self-efficacy within or between groups. The change between groups did not reach statistical significance (Table 23).

Self-management Behaviours

The increase in raw data for each group failed to reach statistical significance at the adjusted p-value < 0.003 . Between groups change was not significant (Table 23).

Shortness of Breath: Severity and Frequency

Participants in the intervention group reported very small decreases in perceived severity and frequency of breathlessness following the programme. There was a very small increase in frequency of perceived shortness of breath and no change in severity of breathlessness for the control group. These differences were not statistically significant. The changes in breathlessness between the groups were not significant. The minimal clinically important difference for people with COPD has not been reported, but that for asthma is reported as 2.2 centimetres (Karras, Sammon & Terregino 2000). No changes reached this difference (Table 24).

Achieving Exercise Criteria

The proportions of participants reporting they met the criteria for exercise participation doubled in the intervention group, and trebled in the control group following the programme. Statistical significance was not reached at the 0.003 level of significance. Due to the sample size there was insufficient data in each category to report statistical significance between groups. However, nearly one-third of participants in each group progressed from not achieving the recommended exercise levels per week to achieving them post the programme (Table 24).

Stage of Change for Exercise

Due to the sample size there were insufficient data in the five categories, to enable reporting of statistical significance. However, by recoding stage of change to represent 'pre-action' (precontemplation, contemplation, preparation) or 'action' (action, maintenance) proportions in the intervention group were increased. There was a non-significant shift from pre-action to action for the intervention group (Table 24).

There were insufficient data in the control group to enable reporting of p-values.

While the changes between the groups did not reach statistical significance, there was a greater proportion of people in the intervention group than in the control group who had progressed to undertaking exercise (31.7% versus 22.5%).

Health-Related Quality of Life

None of the within-group or between-group changes in the SF-36v2 measuring health-related quality of life, reached statistical significance. However, both groups showed small increases in the physical function, role physical and role emotional domains. The intervention group had a greater increase in the physical component summary compared to the control group. The control group increased more for vitality (Table 25).

4.2.8.3 Effect Sizes

Effect sizes were calculated for the changes in outcomes for the intervention and control groups (Table 29). This analysis was carried out as the sample size had not been determined by power calculations for the secondary outcome measures, and being a small sample, statistical significance was difficult to detect.

Table 29: Effect Sizes for Change in Outcomes

Outcome	Intervention (CDSMP+Ex)	Control (CDSMP- Only)	Outcome	Intervention (CDSMP+Ex)	Control (CDSMP- Only)
6MWD	0.15	0.21	SF-36v2		
			Physical Function	0.16	0.18
All exercise: duration	0.42	-0.22	Role Physical	0.23	0.31
All exercise: frequency	0.72	-0.08	Bodily pain	0.18	-0.05
Moderate exercise: duration	0.47	0.21	General Health	0.10	-0.07
Moderate exercise: frequency	0.27	0.07	Vitality	0.13	0.31
Exercise self- efficacy	0.18	0.20	Social Function	0.04	0.29
Self- management behaviours	0.20	0.20	Role Emotional	0.11	0.12
Shortness of breath: Severity	-0.35	0.00	Mental Health	0.02	0.12
Shortness of breath: Frequency	-0.23	0.04	Physical Component Summary	0.26	0.10
			Mental Component Summary	0.03	0.19

Note: Effect sizes: 0.20–0.40 = small; 0.50–0.70 = medium; greater than 0.80 = large.

With the exception of the medium effect size for frequency of all reported exercise in the Intervention group, effect sizes were small or negligible.

4.2.8.6 Post Hoc Analyses: Interviewees versus Not-Interviewed

The intent of the purposeful sampling for the qualitative study was to interview people representative of the group as a whole. A post hoc analysis of baseline demographics and outcome variables was performed to ascertain if those interviewed differed significantly from the remainder of the study group. The baseline and post intervention outcomes were also compared for the interviewed group.

Demographics

There were fewer females interviewed, and a greater proportion married. Interviewees had a higher level of education and socioeconomic status and more were referred by private practitioners. There were also more interviewees with severe COPD compared with those not interviewed. However, none of these differences reached statistical significance (Table 30).

Table 30: Interviewees versus Not Interviewed: Baseline Characteristics

Variable		Interviewees (n = 20)	Not Interviewed (n = 64)	p value
Female		6 (30.0%)	34 (53.1%)	0.121
Not married		7 (35.0%)	27 (42.2%)	0.756
Married		13 (65.0%)	37 (57.8%)	
Education:	to year 8	3 (15.0%)	18 (29.0%)	0.059
	to year 10	7 (35.0%)	30 (48.4%)	
	to year 12	10 (50.0%)	14 (22.6%)	
			2 missing	
Self-Reported Co morbidities: None		16(80.0%)	45 (71.4%)	0.641
Comorbidities		4 (20%)	18 (28.6%)	
			1 missing	
Referral Source: Primary Health,				0.511
Private		11 (55.0%)	26 (40.6%)	
Wards		4 (20.0%)	15 (23.4%)	
Clinics		5 (25.0%)	23 (36.0%)	
Socioeconomic Status:	above median	10 (52.6%)	27 (44.3%)	0.707
	below median	9 (47.4%)	34 (55.7%)	
		1 missing	3 missing	
COPD Grade:	Mild (60–80%)	2 (14.3%)	18 (32.7%)	Not reported
	Moderate (40–59%)	4 (28.6%)	12 (21.8%)	
	Severe (< 40%)	8 (57.1%)	25 (45.5%)	
		6 missing	9 missing	
Age (years)		64.0 ± 7.88	66.3 ± 9.70	0.322

Note: Data are reported as either raw number (percentage) within study group status, as mean ± standard deviation. The p-values are from t tests, Mann-Whitney U tests or chi-square analyses with level of significance p < 0.05.

Baseline Outcome Variables

There were no statistically significant differences between the groups at baseline assessment (Table 31).

Table 31: Interviewees versus Not Interviewed: Baseline Outcome Variables

Variable		Interviewees	Not Interviewed	P value
Primary Outcome		(n = 20)	(n = 62)	
6MWD (metres)		344.3 ± 125.8	354.9 ± 106.1	0.713
Secondary Outcomes		(n = 20)	(n = 61)	
All exercise: duration (hours per week)		7.75 (0 -26.0)	5.75 (0-52.25)	0.814
All exercise: frequency (times per week)		11.5 (0 -36.0)	11.0 (0 -59.0)	0.826
Moderate exercise: duration (hours)		0.50 (0-19.50)	0.50 (0-11.25)	0.562
Moderate exercise: frequency (times per week)		2.0 (0-14.0)	2.0 (0-23.0)	0.585
Exercise self-efficacy (scale 0-5)		2.7 ± 1.3	2.7 ± 1.0	0.996
Self-management behaviours (scale 0-8)		6.4 ± 1.0	6.1 ± 1.0	0.264
Shortness of breath: Severity (centimetres)		7.0 ± 2.5	7.0 ± 2.3	0.956
Shortness of breath: Frequency (centimetres)		7.0 ± 2.7	7.0 ± 2.6	0.700
SF-36v2 Physical Function		30.31 ± 8.61	28.74 ± 8.47	0.478
SF-36v2 Role Physical		30.89 ± 8.35	32.40 ± 10.34	0.556
SF-36v2 Bodily pain		48.70 ± 11.0	44.27 ± 11.56	0.136
SF-36v2 General Health		29.72 ± 8.61	31.88 ± 9.70	0.378
SF-36v2 Vitality		42.10 ± 8.01	40.98 ± 9.85	0.648
SF-36v2 Social Function		43.76 ± 12.56	40.58 ± 12.26	0.319
SF-36v2 Role Emotional		44.99 ± 10.97	34.02 ± 16.01	0.006
SF-36v2 Mental Health		50.71 ± 7.30	45.7143± 11.93158	0.082
SF-36v2 Physical Component Summary		30.10 ± 8.02	32.29 ± 7.57	0.271
SF-36v2 Mental Health Component Summary		52.00 ± 6.79	44.23 ± 13.31	0.015
Achieving Exercise Criteria:	Yes	2 (10.0%)	15 (24.6%)	0.283
	No	18 (90.0%)	46 (75.4%)	
Stage of Change for Exercise:				Not reported
	Precontemplation	3 (15.0%)	7 (11.5%)	
	Contemplation	10 (50.0%)	21 (34.4%)	
	Preparation	3 (15.0%)	13 (21.3%)	
	Action	1 (5.0%)	10 (16.4%)	
	Maintenance	3 (15.0%)	10 (16.4%)	
Recode Stage of Change: Intending		16 (80.0%)	41 (67.2%)	0.421
Acting		4 (20.0%)	20 (32.8%)	

Note: Data are reported as either raw number (percent) within study group status, as mean ± standard deviation. The p-values are from t-tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment.

Interviewees walked 10.6 metres less than those not interviewed, and a greater proportion reported they were not achieving the recommended exercise criteria of 30 minutes of moderate exercise on all or at least five days of the week. Interviewees also tended to have better social functioning, emotional role and mental health and this was reflected in a higher mental component summary score of the SF-36v2 quality of life survey. Their physical component summary score was lower than those not interviewed. Following a Bonferroni adjustment, these differences did not reach statistical significance.

Baseline and Post Outcomes Comparisons

Baseline and post outcomes were analysed for the interviewees, to provide an additional element of triangulation of the data (Table 32). The interviewees showed a statistically significant increase in their 6MWT distance following the programme. There was a significant increase in frequency of all self-reported exercise. Although the remaining domains of self-reported exercise also increased, these failed to reach significance at the 0.003 level. The implications of these results will be discussed in the following chapter.

Table 32: Interviewees: Baseline and Post Outcomes Comparisons

Variable		Baseline	Post	P value
Primary Outcome		(n = 20)	(n = 64)	
6MWD (metres)		344.3 ± 125.8	365.0 (114 -533)	0.012
Secondary Outcomes		(n = 20)	(n = 64)	
All exercise: duration (hours per week)		7.75 (0 -26.0)	11.63 (0-34.0)	0.005
All exercise: frequency (times per week)		11.5 (0 -36.0)	21.0 (0-115.0)	0.001
Moderate exercise: duration (hours)		0.50 (0-19.50)	2.00 (0-30.75)	0.012
Moderate exercise: frequency (times per week)		2.0 (0-14.0)	4.0 (0-19.0)	0.029
Exercise self-efficacy (scale 0-5)		2.7 ± 1.3	3.2 ± 1.0	0.182
Self-management behaviours (scale 0-8)		6.4 ± 1.0	6.8 ± 0.7	0.079
Shortness of breath: Severity (cms)		7.0 ± 2.5	6.8 ± 2.4	0.817
Shortness of breath: Frequency (cms)		7.0 ± 2.7	7.0 ± 2.7	0.676
SF-36v2 Physical Function		30.31 ± 8.61	32.11 ± 8.68	0.139
SF-36v2 Role Physical		30.89 ± 8.35	35.58 ± 11.28	0.025
SF-36v2 Bodily pain		48.70 ± 11.0	50.26 ± 9.67	0.473
SF-36v2 General Health		29.72 ± 8.61	28.15 ± 8.21	0.571
SF-36v2 Vitality		42.10 ± 8.01	43.55 ± 7.20	0.455
SF-36v2 Social Function		43.76 ± 12.56	46.80 ± 8.58	0.274
SF-36v2 Role Emotional		44.99 ± 10.97	45.65 ± 12.91	0.727
SF-36v2 Mental Health		50.71 ± 7.30	49.26 ± 9.86	0.568
SF-36v2 Physical Component Summary		30.10 ± 8.02	32.82 ± 8.44	0.076
SF-36v2 Mental Health Component Summary		52.00 ± 6.79	51.59 ± 9.50	0.962
Achieving Exercise Criteria:	Yes	2 (10.0%)	10 (58.83%)	Not reported
	No	18 (90.0%)	7 (41.2%)	
		1 missing	2 missing	
Stage of Change for Exercise:				
	Precontemplation	3 (15.0%)	0	Not reported
	Contemplation	10 (50.0%)	6 (35.3%)	
	Preparation	3 (15.0%)	1 (5.9%)	
	Action	1 (5.0%)	7 (41.2%)	
	Maintenance	3 (15.0%)	3 (17.6%)	
		1 missing	2 missing	
Recode Stage of Change:				
	Intending	16 (80.0%)	7 (41.2%)	Not reported
	Acting	4 (20.0%)	10 (58.8%)	

Note: Data are reported as either raw number (percent) within study group status, as mean ± standard deviation. The p-values are from t-tests, Mann-Whitney U tests or chi-square analyses with level of significance $p < 0.05$ for 6MWT and $p < 0.003$ for secondary outcomes, following a Bonferroni adjustment.

4.3 Chapter Summary

The analyses reported in this chapter show that the study sample was representative of the population of people with COPD referred to the Physiotherapy Outpatients Department. The statistically significant improvement in the 6MWT distance for both groups and the lack of significant change between the groups will be discussed in the following chapter. Associations with the change in 6MWT distance and selected variables were weak. Frequency of moderate self-reported exercise and exercise self-efficacy explained 7.9% of the variance in distance walked. The change in 6MWT distance for intervention and control groups failed to reach clinical significance.

Statistical significance for within group change was reached for frequency of all self-reported exercise and for duration of moderate exercise for the intervention group. An improvement in outcomes was suggested in self-management behaviours and role physical of the SF-36v2 questionnaire for each group. There were increases in physical function and the physical component summary and a decrease in breathlessness severity for the intervention group; and increases in the proportion achieving exercise criteria, vitality and social function for the control group. However, statistical significance was not reached at the adjusted p -value < 0.003 following a Bonferroni adjustment.

There were no statistically significant changes between the groups. With the exception of frequency of all self-reported exercise for the intervention group, effect sizes were small.

There were no significant differences in demographic or outcome variables at baseline between interviewees and those not interviewed. However, the data suggest interviewees were better educated and from a higher socioeconomic group, despite having more severe COPD. Nevertheless, comparisons pre and post the programme reflected those of the larger study group.

The results of the analyses, patterns of referral and reasons for attrition will be discussed in the following chapter.

5

CHAPTER FIVE:

DISCUSSION OF QUANTITATIVE OUTCOMES

5.1 Introduction

The primary purpose of this study was to inform clinical practice at our hospital and elsewhere as to the effect of adding supervised exercise to the CDSMP. This was rigorously evaluated in a clinical setting. Physical capacity, measured by the distance walked in the 6-minute walk test, was the selected primary outcome measure. As explained in *Chapter Three*, this test is reflective of the capacity to undertake the physically demanding activities of daily life, is simple to perform, does not require sophisticated equipment or training and is a frequently studied outcome in cardiopulmonary rehabilitation. A variety of secondary outcomes were measured to provide additional insight into the effect of attending supervised exercise as well as the CDSMP.

The literature reviewed in *Chapter Two* pointed to a significant increase in self-reported aerobic exercise following attendance at CDSMPs. In light of this, the null hypothesis was that the addition of supervised exercise to the CDSMP would not result in a greater change in distance walked by participants attending the CDSMP with supervised exercise than those attending the CDSMP without supervised exercise. As the secondary outcomes were exploratory in intent, hypotheses were not generated.

The results of the primary and secondary outcomes analyses are discussed below. Conclusions are drawn and implications for clinical practice suggested.

5.2 Key Results

The results of this randomised controlled clinical trial, analysed on an intention-to-treat basis, highlight a number of points.

1. Primary outcome analyses: Distance walked in 6MWT ($p < 0.05$)

- There was no significant difference between the CDSMP with supervised exercise and the CDSMP without supervised exercise on physical capacity as measured by the distance walked in the 6MWT. Thus the null hypothesis was supported.
- There were small statistically significant increases in the 6MWT distance for both the intervention and the control groups. The effect size was small for both groups (0.15, intervention and 0.20, control) and a clinically significant increase of 54 metres was not reached.

2. Secondary outcome analyses ($p < 0.003$ following a Bonferroni adjustment)

- There were no statistically significant differences in the changes between both groups for any secondary outcome measure.
- The CDSMP with or without supervised exercise resulted in similar small, albeit not statistically significant, improvements in:
 - physical function, role physical and role emotional domains of quality of life
 - exercise self-efficacy
 - self-management behaviours
 - facilitation of exercise adoption.
- The addition of supervised exercise to the CDSMP had greater effect (small to medium) than no supervised exercise on:
 - increasing duration and frequency of moderate exercise.
Increases in frequency of all exercise and duration of moderate exercise were statistically significant for the intervention group.
 - decreasing breathlessness
 - increasing physical component summary of the SF-36v2.

- The control group demonstrated no significant improvements in any secondary outcome.
- The control group experienced greater improvements in vitality and social function of the SF-36v2 than did the intervention group. Effect sizes were small.

3. Associations

- Correlations with the change in 6MWT distance were weak ($r < 0.3$), the strongest being frequency of moderate exercise ($r = -0.188$, $p = 0.066$) and exercise self-efficacy ($r = 0.140$, $p = 0.132$). None reached statistical significance in this small sample.
- When entered in a multivariable linear regression model, the frequency of moderate exercise and exercise self-efficacy explained 7.9% of the variance in the change in the 6MWT distance.

4. Referral Sources and Attendance Patterns

- Participants enrolling in the programme were more likely to have been referred by private specialists or primary healthcare professionals.
- Just over one quarter of all those referred enrolled in the programme. However, once the programme commenced over 80% of participants completed post programme data collection. The majority of participants completed 5 or more of the CDSMP or supervised exercise sessions.

5. Reasons for Attrition

- The most cited reasons for non-attendance at screening appointments were unsuitability of the programme and being unwell.
- Reasons for non-participation in the study were predominantly having other commitments or unsuitability of the programme.
- Reasons for not attending CDSMP or supervised exercise sessions were mostly health related or due to other commitments.

These outcomes will be discussed in detail below.

5.2.1 Primary Outcome: 6-Minute Walk Test Distance

5.2.1.1 Between-Group Differences and Within-Group Change

Both intervention and control groups in this study had a significant increase in their 6MWT distance. The direction of change in the intervention group is consistent with the COPD-related literature published over the past eight years: a recently published updated systematic review (Lacasse et al. 2006); randomised controlled studies (Elliott et al. 2004; Finnerty et al. 2001; Singh et al. 2003; Troosters, Gosselink & Decramer 2000) and cohort studies (Cockram, Cecins & Jenkins 2006; Hui & Hewitt 2003; Miyahara et al. 2000). However, the magnitude of change (18.6 ± 46.2 metres) is at the lower end of the range of improvement reported in the literature (Table 33). The mean distance of 352.3 ± 110.5 metres walked by the whole study group, nearly half of whom had severe COPD, is comparable to that reported in other studies of people with severe COPD (Martinez et al. 2006; Sciurba et al. 2003).

The change in walking distance did not differ significantly between the intervention and control groups in my study. Methodological differences between published studies and this render comparisons difficult. For example, many studies do not report the difference between groups, making it difficult to know if any disparity is statistically significant (Table 33). Of those reporting the difference, one showed the intervention group of supervised exercise and education versus community-based exercise walked further but the difference between the groups was not statistically significant at the usually accepted level (Elliott et al. 2004). In another study, education and supervised exercise versus usual care resulted in a non-statistically significant increase in distance walked for the intervention group, a decrease for controls but no significant difference between groups (Ringbaek et al. 2000). One study referred to as a self-management intervention, a home-based programme with telephone follow-up versus usual care (Bourbeau et al. 2003) also reported no statistically significant difference within or between groups. However, statistical significance was not reported..

Two studies found a statistically significant difference between groups in favour of the intervention group receiving an outpatient supervised exercise programme (Troosters, Gosselink & Decramer 2000) or supervised exercise, education and counselling (Griffiths et al. 2000) versus usual care. There was an increase in

distance walked for the intervention group but not controls in Griffiths et al.'s study but statistical significance was not reported. Singh et al. (2003) and Finnerty et al. (2001) found a significant increase in 6MWT distance for the intervention group and not controls, but did not include between-groups differences. Similarly, a nurse-led group-based programme with near-home supervised exercise, referred to by the authors as self-management, versus usual care (Monninkhof 2003) did not include between group differences. In contrast to my study, the authors found a small non-statistically significant decrease in distance walked for both the intervention and control groups. These studies demonstrate the importance of reporting not only within-group changes, but especially between-groups' differences. Without reporting between-groups differences, it is impossible to conclude that the intervention is more effective than the control.

Explanations for the lack of significant difference between groups in my study and for the small but statistically significant increase in distance walked by both groups are discussed below. Additionally, the lack of clinical significance of my results will be considered.

Table 33: Details of Cardiopulmonary Rehabilitation Studies: Exercise Sessions and Change in Distance Walked (2000–2008)

Author (year)	Intervention Details	Supervised Exercise Sessions					Change in 6MWT Distance (metres)		
		Duration (weeks)	Frequency of Supervision	Total number	Duration per session (mins)	Total Hours	Intervention	Control	Between Groups
Elliott et al. (2004)	Out-patient education and supervised exercise versus community exercise (first stage) RCT. Outcomes measured at 12, 24 and 52 weeks. 12 week outcomes reported here.	12	2 per week	24	90	36, 3 hours per week	81.3 ± 18.3 p<0.01	14.4 ± 28.6 NS	Values not reported p = 0.058
Bourbeau et al. (2003)	At home education and one supervised exercise session, encouraged to follow home programme, with telephone follow-up versus usual care RCT. Outcomes measured at 12 and 52 weeks.	44	Encouraged 3 per week	132	Encouraged 30–45	66–99, 1.5–2.25 hours per week	Values not reported NS	Values not reported NS	Values not reported NS
Monninkhof et al. (2003)	Education and near-home supervised exercise with exercise diary versus usual care RCT. Outcomes measured at 52 weeks.	104 (2 years)	1–2 per week	104–208	60	104–208, 1–2 hours per week	-13 ± 7 NS	-2 ± 5 NS	Not reported
Singh et al. (2003)	Home-based walking twice a day, supervised once per week versus usual activities. Parameters of the home-based programme are listed, although each session was not supervised. RCT. Outcomes measured at 4 weeks.	4	1 per week	56	30	28, 4 hours per week	54.2 ± 26.7 p<0.001	6.7 ± 10.3 NS	Not reported

Note: RCT = randomised controlled trial. Adherence to home exercise programmes was not reported, so actual hours spent undertaking unsupervised exercise cannot be included in the table.

Table 33 (continued)

Author (year)	Intervention Details	Duration (weeks)	Frequency of Supervision	Exercise Sessions		Total Hours	Change in 6MWT Distance (metres)		
				Total number	Duration per session (mins)		Intervention	Control	Between Groups
Finnerty et al. (2001)	Out-patient education, supervised exercise, with home programme versus usual care RCT. Outcomes measured at 12 and 24 weeks. 12 week outcomes reported here.	6	1 per week	6	60	6, 1 hour per week	51 (20, 81) p<0.02	Values not reported NS	Not reported
Griffiths et al. (2000a)	Outpatient education, supervised exercise, counselling versus usual care RCT. Outcomes measured at 6 and 52 week.	6	3 per week	18	30	9, 1.5 hours per week	Shuttle walk test, increase p-value not reported	Shuttle walk test, decrease p-value not reported	Shuttle walk test, 75.9 p = 0.000
Ringbaek et al. (2000)	Out-patient education, supervised exercise versus usual care RCT. Outcomes measured at 8 weeks.	8	2 per week	16	60	16, 2 hours per week	10.5 ± 45.0 NS	-18.5 ± 62.0 NS	29 (-8, 66) NS
Troosters et al. (2000)	Out-patient supervised exercise versus usual care RCT. Outcomes measured at 24 weeks.	24	3 per week for 12 weeks, 2 per week for 12 weeks	36+24= 60	90	90, 3.75 hours per week	p-value not reported	p-value not reported	52 (15–89) p = 0.01

Note: RCT = randomised controlled trial. Adherence to home exercise programmes was not reported, so actual hours spent undertaking unsupervised exercise cannot be included in the table

Table 33 (continued)

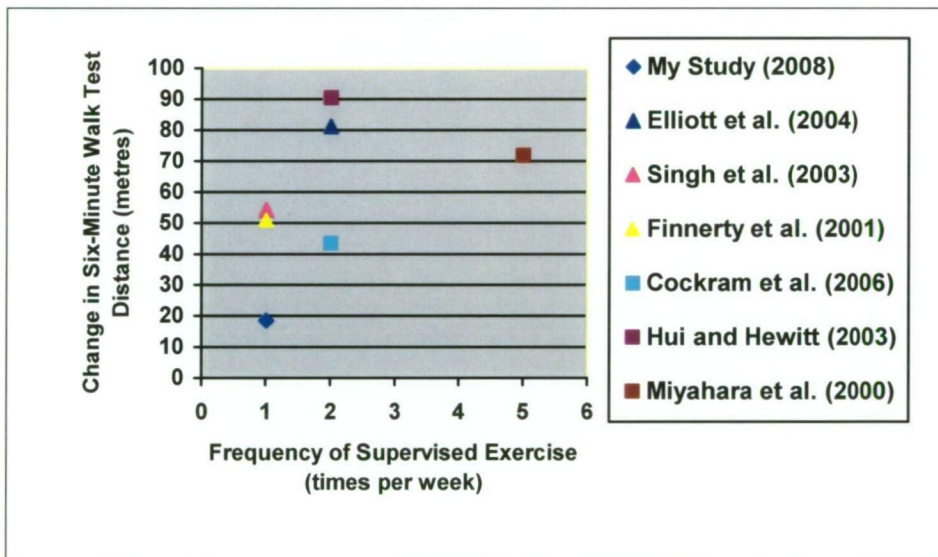
Author (year)	Intervention	Exercise Sessions					Change in 6MWT Distance (metres)		
	Details	Duration (weeks)	Frequency	Total number	Duration per session (mins)	Total Hours	Intervention	Control	Between Groups
Skumlien et al. (2007)	In-patient education, individual exercise, optional group exercise, counselling versus usual care Uncontrolled Trial. Outcomes measured at 4 weeks.	4	4 -5 per week	16 -20	20	5.5–6.6, 1.25–1.65 hours per week	14 (-4, 31) p = 0.132 NS	-5 (-23, 14) p = 0.622 NS	Not reported
Cockram et al. (2006)	Out-patient education, supervised exercise, encouraged to follow home programme Cohort Study. Outcomes measured at 8 weeks.	8	2 per week	16	60–80	16–21, 2–2.6 hours per week	43.6 (19.9, 67.2) p<0.01	Not applicable	Not applicable
Hui and Hewitt, (2003)	Out-patient supervised exercise Cohort Study	8	2 per week	16	90	24, 3 hours per week	90.5 ± 63 p < 0.001	Not applicable	Not applicable
Miyahara et al. (2000)	In-patient education, supervised exercise Cohort Study. Outcomes measured at 4 weeks.	3	5 per week	15	20	5, 1.6 hours per week	71.9 p < 0.05	Not applicable	Not applicable

Note:.. Adherence to home exercise programmes was not reported, so actual hours spent undertaking unsupervised exercise cannot be included in the table

Frequency of sessions

The characteristics of the studies that found a statistically significant increase in 6MWT distance for the intervention group suggest that the frequency of exercise sessions may explain the magnitude of any increase in 6MWT (Cockram, Cecins & Jenkins 2006; Elliott et al. 2004; Finnerty et al. 2001; Griffiths et al. 2000; Hui & Hewitt 2003; Miyahara et al. 2000; Singh et al. 2003; Troosters, Gosselink & Decramer 2000). There appears to be a positive association between the frequency of supervised exercise (sessions per week) and the increase in distance walked (Figure 8).

Figure 8: Influence of Exercise Frequency and Change in 6MWT Distance



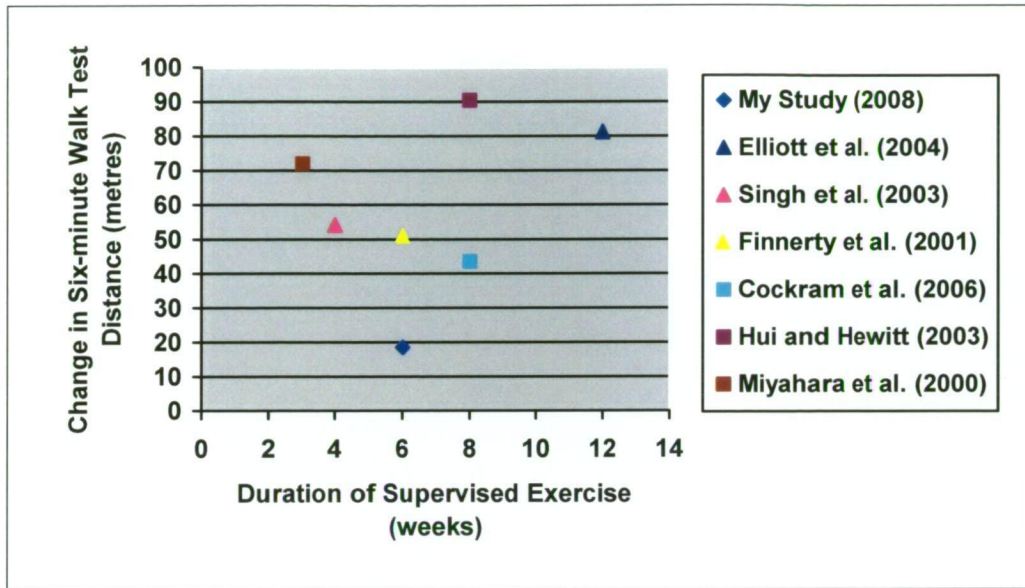
Legend: ▲ = randomised controlled studies; ■ = cohort studies

Similar to my study, Singh et al. (2003) and Finnerty et al. (2001) had supervised exercise once per week. However, in contrast, these researchers included an unsupervised home walking programme of twice a day (Singh et al. 2003) or five days a week (Finnerty et al. 2001) in the intervention, thereby increasing the frequency of weekly walking. Additionally, Finnerty et al. (2001) measured outcomes at 12 weeks and did not report home-based walking during this time, so it is unknown if the participants continued or varied their schedule. Participants in my study reported undertaking moderate exercise only three times per week post the intervention. In accordance with the CDSMP protocol, the type of exercise was not specified and walking may not have been the exercise of choice. The study participants appear to have exercised less frequently than those in Singh et al.'s

(2003) and Finnerty et al.'s (2001) studies. This may explain the smaller increase in distance found, compared with these researchers, when each intervention had supervised exercise only once per week.

The American Thoracic Society (Nici et al. 2007) recommends at least two, preferably three supervised exercise sessions weekly. Ringbaek et al. (2000) found no significant within-group or between-groups differences in the 6MWT distance following eight weeks of education with supervised exercise versus usual care for people with moderate COPD, concluding that supervised exercise twice per week is insufficient. However, Singh et al. (2003), Finnerty et al. (2001) and my study point to the importance of frequency of exercise per se, bringing into question the optimal degree and type of supervision required to significantly increase physical capacity by a moderate to large amount. Once per week supervision with a structured home programme may be sufficient. My results suggest that once per week without a structured home programme is insufficient to have more than a small effect on improving physical capacity.

While it is recognized that duration of exercise will also influence the effect on the 6MWT distance, there appears to be little association between total duration of the intervention and the distance walked (Figure 9). Frequency of exercise per week may have more of an effect on distance walked in the 6MWT.

Figure 9: Influence of Intervention (Exercise) Duration and Change in 6MWT Distance

Legend: ▲ = randomised controlled studies; ■ = cohort studies

Although the frequency of supervised exercise appears to influence the increase in 6MWT distance for intervention groups, controls in my study also walked significantly further. This contrasts with other studies that found no significant increase for control groups (Table 33). An explanation of the small increase in both groups in my study follows.

The CDSMP: A self-regulation of behaviour approach

The small significant increase in distance walked for both groups and lack of significant change between the groups may be explained by the behavioural approach underlying the CDSMP. The qualitative data support this rationalisation. Interviewed participants revealed that setting goals and completing action plans for self-regulated exercise helped them to consider themselves and learn that they could achieve their goals. As the following chapter will make clear, this appeared to facilitate self-efficacy through mastery (achieving the exercise level) and reappraisal of stressors such as fear of breathlessness. The CDSMP employs the use of behavioural strategies grounded in psychological theory, one of which is social cognitive theory (Bandura 1977, 1986). Participants are guided to develop self-regulation of behaviour by setting personally relevant goals and then following a plan of action to achieve the goal. Learning to self-regulate in this way may be more important for improving physical capacity than supervision of exercise per se.

The study reported in this thesis differs from others referred to in Table 33 in that it is the only study to report a statistically significant mean increase (20.0 metres) in 6MWT distance for controls. An explanation for this is that participants received a behaviourally based educational intervention, contrasting with controls in other studies. In most studies, control groups are assigned to usual medical care (Bourbeau et al. 2003; Finnerty et al. 2001; Griffiths et al. 2000; Monninkhof, E. et al. 2003; Ringbaek et al. 2000; Skumlien et al. 2007; Troosters, Gosselink & Decramer 2000) or usual activities (Singh et al. 2003), whereas controls in my study attended the CDSMP.

One early study that assigned controls to education sessions concerning anatomy and physiology of COPD, medication use and health behaviours versus supervised exercise plus education sessions concluded that education alone does not improve physical capacity (Wedzicha et al. 1998). Although the CDSMP is an educational intervention, it is grounded in psychological theory to facilitate behaviour and therefore differs from the format of most education-only approaches. As the results of my study show, attending the CDSMP by itself improves physical capacity. While there is a lack of published studies reporting the 6MWT distance following the CDSMP only, support for the increased physical capacity for controls in my research comes from one other study that reported a mean increase of 39 metres in distance walked during the incremental shuttle walk test for 18 participants post attendance at a CDSMP (Murphy et al. 2004). However, statistical significance was not reported.

The data do show a small statistically significant increase in physical capacity as measured by the 6MWT for both intervention and control groups. These data do support the conclusion that the CDSMP does not need to be augmented by supervised exercise to effect a small statistically significant increase in physical capacity. However, the change did not reach the accepted minimal clinically important difference of 54 metres (Redelmeier et al. 1997). The challenge now is to target variables explaining this small increase, and investigate whether or not the small positive result can be augmented.

Minimal Clinically Important Difference

The majority of intervention or control participants in this study did not increase the 6MWT distance by the acknowledged minimal clinically important difference of 54

metres. While this is the currently accepted clinically significant threshold, the difference of 54 metres was determined by subjective comparisons of individuals with others, and not by enquiry as to what may represent an important functional change for the individual with reference to daily activities, it is not known what a self-referent value might be. The 6MWT reflects an individual's capacity to carry out their activities of daily living (Guyatt et al. 1985), therefore it would seem reasonable to determine a minimal clinically important difference with reference to personally relevant activities, rather than to the distance walked by others. Self-referent values for distance walked have been recently reported for the incremental shuttle walking test (47.5 metres (95% CI 38.6 to 56.5 metres)(Singh et al. 2008). The distance at which participants noted their distance walked to be 'about the same' was 18.0 metres (95% CI 4.6 to 31.5), similar to the changes in 6MWT distance observed in my study. Self-referent determinations do not appear to have been studied for the 6MWT. Such determinations would need to be the subject of future research.

Additionally, as the qualitative findings presented in the following chapter will show, participants spoke of a benefit from their exercise, regardless of the change in distance walked, pointing to the importance of listening to participants' voices. What participants in this study tell us is different to what is suggested as a minimal clinically important difference for the 6MWT distance. Clinical importance, for example the distance walked as a predictor of morbidity and mortality (Martinez et al. 2006), differs to functional importance from an individual perspective. Small changes may be relevant to individuals whose function may be compromised and future research is needed in this area.

In summary, while the CDSMP does not need to be augmented by supervised exercise to effect a statistically significant increase in physical capacity, the small change is not clinically significant. It did not reach the currently accepted minimal clinically important difference of 54 metres. Research concerning the minimal clinically important difference needs to be extended to investigate self-referent values. Further research is needed to determine whether small changes are functionally relevant to people whose physical capacity is already compromised.

5.2.1.2 Associations with the 6MWT

Multiple linear regression analysis showed correlations with the change in 6MWT distance to be weak. The final model, which included frequency of moderate self-reported exercise and exercise self-efficacy, explained only 7.9% of the variance in the 6MWT distance. Although the model did not reach statistical significance ($p = 0.075$), it points to implications for clinical practice.

Frequency of Moderate Self-reported Exercise

Frequency of moderate exercise made a significant unique contribution to the variance ($\beta = -0.257$, $p = 0.048$). Individuals walking less frequently at baseline can expect a greater increase in 6MWT distance post programme. The clinical implications are that enquiry should be made as to the *frequency* of moderate exercise, and not only duration. For people with COPD this result is relevant: many must exercise more frequently to accumulate the minimum recommendation of 150 minutes per week on at least 5 days. For those who are less frequently active, barriers to exercise frequency could be explored and problem solving initiated to address the barriers.

Exercise Self-efficacy

Exercise self-efficacy did not make a significant unique contribution to the change in distance walked ($p = 0.089$). However, as confounding existed between this variable and frequency of moderate exercise, it was retained. The model indicates that people with higher self-efficacy have a greater increase in change in 6MWT distance, supporting psychology theory as discussed earlier (Bandura 1986).

The clinical implications are that enquiry should be made of participants attending rehabilitation programmes aiming to increase physical capacity as to their 'confidence' (self-efficacy) to exercise and strategies for fostering exercise self-efficacy implemented if required.

5.2.1.3 Hawthorne Effect

Consideration of the so-called Hawthorne effect (Polgar & Thomas 2000) would suggest that participants in the control group improved their physical capacity because of the attention they received, regardless of the intervention. However, the study was designed to exclude this with exercise sessions being held independently

of the CDSMP and participants being requested not to discuss their exercise experiences during the CDSMP. Intervention and control groups attended the CDSMP together, thereby receiving similar attention. The similar increase in 6MWT distance for each group is not explained by a Hawthorne effect. What may be an important factor in increasing distance walked is the *type* of intervention and its behaviour theoretical underpinnings, not whether exercise is supervised.

5.2.2 Secondary Outcomes

The intervention group demonstrated statistically significant increases in frequency of all self-reported exercise and duration of moderate self-reported exercise. All other outcomes were not statistically significant, following a Bonferroni adjustment ($p < 0.003$) (Pallant 2005). There were no significant differences between the groups. These results are discussed below.

5.2.2.1 Self-Reported Exercise

In this study, the difference between intervention and controls for self-reported exercise was not statistically significant. Few studies in the CDSMP literature have reported the difference between the intervention and control groups. Only two studies (Table 7) reported between group differences immediately post CDSMP. In support of this study, both found no significant difference between participants attending the CDSMP versus usual care (Elzen et al. 2007) or Tai Chi classes (Siu et al. 2007).

Although the difference between groups in my study for self-reported exercise was not statistically significant, analysis of effect sizes favoured the intervention group in the four domains. When analysed in this way, the benefit of supervised exercise with the behavioural approach of the CDSMP supports that of Atkins et al. (1984) who observed that participants with COPD receiving a cognitive-behavioural approach with supervised exercise reported significantly more walking than comparison groups. The effect sizes were predominantly small for the domains of self-reported exercise in the intervention group in my study. However, a small effect size may be relevant for a group whose physical activity is much compromised. The qualitative findings in the following chapter suggest that small improvements were important to

the participants, for example, in developing exercise self-efficacy and in undertaking more physical activities.

Self-reported exercise changed very little for controls attending only the CDSMP, statistical significance was not reached and effect sizes were small or negligible. Indeed, the duration of all self-reported exercise showed a small median decrease (Table 23). The results differ to the 61.5% (8/13) of studies reporting a significant increase in self-reported exercise following the CDSMP (*Chapter Two*). However, most studies reported outcomes measured at four, six or 12 months post CDSMP, making it difficult to compare change with an immediate post-programme effect. Only three of these studies reported exercise behaviour immediately following the CDSMP (Elzen et al. 2007; Farrell, Wicks & Martin 2004; Siu et al. 2007). In contrast to my study, Siu et al. (2007) and Farrell et al. (2004) reported increases in duration of exercise for participants following the CDSMP, although statistical significance was only reached in Siu et al.'s (2007) study. Elzen et al. (2007) did not report within group results.

One explanation as to why a minimal change in self-reported exercise was found in my study, when others report increases, could lie with the exercise measure. The measure of self-reported exercise used in my study is more comprehensive than the Stanford measure (Lorig et al. 1996) used by other researchers. The Stanford measure enquires about minutes spent exercising per week for specified activities (stretching and strengthening, walking, swimming, cycling, other aerobic activities) and does not differentiate between all levels of reported exercise. This study focussed on moderate exercise, particularly because it is acknowledged as conferring health benefits (*Chapter One*). Additionally, the Stanford measure does not enquire as to exercise during a 'typical' week, rather it asks about the last week, which could be atypical. My results show that using a more comprehensive measure of self-reported exercise yields a more detailed analysis of the effect of the CDSMP on this activity.

The small decrease observed in the median duration of all exercise could be as a result of participants in the control group focusing on other aspects of their lives rather than exercise. This explanation finds support in the HRQoL outcomes. Controls experienced a greater change in vitality and social function domains of the SF-36v2 questionnaire (Table 23). In keeping with the CDSMP protocols,

participants were free to set individually defined action plans. Controls may have chosen more socially aligned activities at the expense of exercise. Smaller changes in all domains of self-reported exercise lend support to this possible explanation. However, without recording and analysing action plans, such a definitive conclusion cannot be made.

Inspection of my data for the duration and frequency of moderate exercise reveals neither group in this study attained all of the minimum recommendations for moderate activity, that is, 30 minutes on at least five days a week or a total of at least 150 minutes per week. The intervention group attained 1.75 hours (105 minutes) and the control group 1.38 hours (82.8 minutes) per week of moderate exercise over three days, following attendance at the programme. This equates to an average of 35 (intervention) and 28 (control) minutes per day on each of three days. It is encouraging that on average, minimum recommended duration was met by the intervention group, even though the recommended frequency per week was not achieved. There is scant reference in other CDSMP studies to attaining minimum recommendations for exercise following the programme. This appears to be the first study to do so.

These results highlight the importance of considering the effect of supervised exercise in different ways. To have focused only on statistical significance would have omitted reporting that the intervention group achieved the recommended duration of at least 30 minutes of moderate exercise over the days they exercised, and the control group fell just short of this. It would also have precluded consideration of effect sizes favouring the intervention group and indicating for both groups a greater effect of participating in the study on duration of exercise rather than frequency. This points to the advisability in clinical practice of exploring ways of increasing the frequency of moderate exercise per week for people with COPD, especially as this was positively associated with the 6MWT distance.

The outcomes of the four self-reported exercise domains suggest that individuals may need not only information concerning a home-based exercise programme, but also practise to allow them to attain the minimum recommended levels of duration, and in particular, frequency of exercise. During the CDSMP guidelines for exercise are addressed, but there is no practise of these recommendations. The supervised

exercise group afforded not only development of mastery for different exercises, but also interpretation of response, peer support, and identification with like others, all of which were identified by most interviewed participants as important elements in the experience of supervised exercise and which are discussed with the qualitative findings.

5.2.2.2 Exercise Participation and Stage of Change for Exercise

A dichotomous question addressing the criteria for minimum recommended levels enabled measurement of the proportion of people who did progress to exercising moderately for 30 minutes on all or at least five days a week. Although there were insufficient data to report statistical analysis, the results show little difference between intervention and controls (31.7% versus 30.0%). The message from these data is that supervised exercise of one hour per week is not a necessary addition to the CDSMP for individuals to progress their exercise behaviour. The stage of change questionnaire results supports this outcome: 31.7% intervention and 22.5% controls had progressed to undertaking exercise. These results call into question suggestions that the CDSMP is suitable only for people who are at an action stage of change for health-related behaviours when they commence the programme (H Lidner 2005, pers. comm., May 10th).

The results suggest that a non-stage based intervention may facilitate positive movement across the 'intention-behaviour gap' (Sniehotta, Scholz & Schwarzer 2005). While acknowledging that a larger study may need to be conducted to determine statistical significance, the CDSMP appears to facilitate the translation from intending to exercise to exercising, whether or not supervised exercise is a component. One explanation may be self-efficacy enhancement. As noted previously, participating in supervised exercise affords mastery, feedback of performance, and comparison with role models, all of which are acknowledged elements in facilitating self-efficacy development (Bandura 1986). As exercise self-efficacy develops, according to psychological theory, movement towards taking action (exercising) is said to occur (Prochaska & Velicer 1997).

It is noted that while both intervention and controls progressed to exercising, as the analysis of the CHAMPS questionnaire showed, those who experience supervised exercise undertake moderate exercise more frequently and for longer periods of time.

This is an important observation for clinical practice. The CDSMP alone will facilitate the adoption of exercise. The addition of supervised exercise increases the positive effect on frequency and duration of moderate exercise, and as such should be encouraged. However, the ‘supervision’ may not need to be group-based. As the qualitative findings revealed, not all individuals require group-based supervision. Clinicians can offer supervision face-to-face or remotely via information technology.

5.2.2.3 Health-Related Quality of Life

Both intervention and controls had small improvements in physical function, role physical and role emotional of the SF-36v2 quality of life measure. However, when combined with the data to form the physical component summary, the effect size shows a benefit of supervised exercise for the intervention group (0.26) and negligible effect for controls (0.10). The difference between the groups was not statistically significant.

The control group experienced greater improvements in vitality, social function and mental component summary than the intervention group. While there were no significant differences at baseline, the control group had lower scores for these domains, allowing greater changes post programme. There were no significant differences in the change between the groups.

These data indicate that people with COPD have a generally low quality of life, evidenced by all mean scores being less than the United States population means, and many below the 25th percentile. Participants in both groups had lowest mean scores for physical function, being below 30 pre-intervention and below 32 post-intervention. The 25th percentile score for 65–74 year old adults in the United States is 35.99 (Ware, Kosinski & Dewey 2000) This is not surprising for a group of people whose physical functioning becomes progressively curtailed as the condition progresses, an observation supported by the qualitative data reported in the following chapter.

The people in this study also had poor mental health, with participants in the intervention and control groups having baseline mental component summary scores of 46.7 ± 12.85 and 45.5 ± 12.17 respectively. These scores are well below the United States population mean of 53.2 ± 9.29 for older adults aged 65–74 years, and are also

lower than the 25th percentile of 49.4 ± 9.29 (Ware, Kosinski & Dewey 2000). My results suggest that enquiry about emotional state should be made of individuals with COPD at clinical encounters and intervention offered if required.

These data support that of the only other published randomised controlled trial to use the SF-36 (version 1) questionnaire as an outcome measure of the CDSMP (Elzen et al. 2007). To reduce the number of comparisons, these authors only reported the component summary scores. Similar to this thesis, the authors found no statistically significant difference between groups for the physical or mental component summary scores. As with the participants in my research, Elzen et al.'s (2007) subjects who attended a CDSMP with no supervised exercise also experienced lower mean physical component summary scores (35.4 ± 10.9) than mean mental component summary scores (46.8 ± 10.1). These scores were lower than the general population. The participants in my study had comparable mental component summary scores but lower physical component summary scores than those in Elzen et al.'s (2007) study.

Elzen et al. (2007) did not report power calculations to determine sample size. However, using the equation suggested by Bowers (2002), a sample size of 63 in each arm would have an 80% probability of detecting a significant change with 95% confidence. That is, $N = 2 \times SD^2 / E^2 \times k = 2 \times 10^2 / 5^2 \times 7.8 = 63$; where SD is the standard deviation, E the minimal clinical important difference and $k = 7.8$ for 80% probability at an alpha of 0.05. Therefore, Elzen et al.'s (2007) sample size of 68 intervention and 68 control would be adequate to detect a significant change, while my study is underpowered (41 intervention, 40 control). This suggests the need to extend the work with a sample size with sufficient power to detect a minimal clinical important difference, which has been suggested as being five points (Lincoln 2000). Nevertheless, my study points to a benefit of supervised exercise with the CDSMP for the physical health components of health-related quality of life.

5.2.2.4 Shortness of Breath

Participating in supervised exercise with the CDSMP resulted in improvements in shortness of breath (SOB) although statistical significance was not reached. There was negligible change for controls. Differences between groups were not statistically significant.

Although a minimal clinically important difference for severity of breathlessness has not been defined for people with COPD, in acute exacerbations of asthma it is 1.1–3.4 cm (Karras, Sammon & Terregino 2000) and 1.23–2.99 cm for people with heart failure, (Ander et al. 2004). Both these groups may experience extreme breathlessness, similar to those with COPD. The decrease of 0.9 ± 2.4 centimetres (cm) for severity of breathlessness in the intervention group lies outside the minimal clinically important difference for these two groups. However, the results point to a small benefit of supervised exercise with the CDSMP in decreasing breathlessness. This is in keeping with the decrease in dyspnoea post cardiopulmonary rehabilitation found by others (Foglio et al. 1999; Griffiths et al. 2000; Miyahara et al. 2000) and with the cognitive–behavioural study by Stulbarg et al. (2002), wherein participants experiencing supervised exercise reported significantly less breathlessness than those who did not have supervised exercise.

The control group did not experience any change in breathlessness. This is consistent with the results of a recently published systematic review (Foster et al. 2007) that also found negligible changes in breathlessness following the CDSMP (standardised mean difference -0.09, 95% confidence interval -0.25 to 0.06). The present results are possibly influenced by the negligible changes in frequency and small changes in duration of moderate self-reported exercise. Without the experience of desensitisation to dyspnoea that the supervised exercise sessions are purported to provide (Carrieri-Kohlman et al. 1996), controls may have felt anxious about increasing their daily physical activity, especially frequency, in an unsupervised environment beyond that to which they were accustomed. I did not measure anxiety associated with dyspnoea or self-efficacy for managing breathlessness. In future studies, these outcomes would provide additional useful information in evaluating interventions for people with COPD.

5.2.2.5 Exercise Self-efficacy

Both intervention and control groups experienced an increase in exercise self-efficacy, but statistical significance was not reached, and the effect size was small. The change between the groups was not significantly different.

Lack of significance for the observed increase in exercise self-efficacy for the intervention and control groups could be explained by considering participants may

have benefited from more individually tailored advice and the feedback that comes from recording activities, as in the case of participants in a study employing cognitive-behavioural strategies similar to the CDSMP (Atkins et al. 1984). These investigators demonstrated that participants who had received specific training in setting action plans for walking in their home setting experienced a significant improvement in walking self-efficacy compared with those who did not ($p < 0.001$).

Like the participants in Atkins et al.'s study (1984) the present participants practised setting action plans and reported benefitting from feedback. However, participants in my study were not requested to record daily exercise nor given any individual exercise prescription to follow at home, other than general guidelines and advice during the CDSMP, in accordance with the protocols for delivering the programme. Additionally, in keeping with the programme's direction, action plans were solely determined by the participants. Hence exercise was not specifically recommended.

Perhaps more specific guidance and recommendations for specific exercise, such as walking or strengthening exercises, would have augmented exercise self-efficacy, especially if a participant set an exercise-related action plan. This is a theoretically feasible argument, especially when consideration is given to the studies showing an increase in walking self-efficacy for people with COPD following an intervention targeting walking (Atkins et al. 1984; Carrieri-Kohlman et al. 1996; Gormley et al. 1993; Toshima, Kaplan & Ries 1990) and following pulmonary rehabilitation of which supervised exercise is a component (Heppner et al. 2006; Lox & Freehill 1999; Ries et al. 1995; Ries et al. 2003), or following a dyspnoea self-management intervention combined with walking (Davis et al. 2006).

The lack of significant outcome for either group may lie with the self-efficacy instrument itself. The respiratory nurse who supervised the completion of questionnaires recorded reasons if participants refused to answer a question or experienced difficulty in understanding the hypothetical nature of the questions, for example, 'My degree of confidence to exercise when I don't have access to exercise equipment is . . . ' Some participants did not see the question as relevant to them and did not answer it because they do not use equipment when exercising. The nurse reported that the hypothetical nature of the questions also posed difficulties in

interpretation for many participants. These observations require more rigorous investigation.

This instrument may not have sufficient sensitivity to changes in exercise self-efficacy for this group of people. Additionally, the primary outcome measure was distance achieved in a walking test and, as self-efficacy is deemed activity-specific (Bandura 1986), a specific question relating to walking-for-exercise self-efficacy may have yielded more robust results. However, as I was evaluating the CDSMP with or without supervised exercise that included walking, upper and lower limb exercises and exercises of personal choice, I chose a scale that enquired about confidence to undertake exercise in general in a variety of situations. Power for the secondary outcomes was not calculated, and the study may have been insufficiently powered to detect a significant change.

Sub-group analyses of the interviewees (11 intervention and 9 controls) showed that exercise self-efficacy also increased and, consistent with the total study outcomes, this difference did not reach statistical significance. However, as it will be revealed in the following chapter, participants overwhelmingly endorsed setting action plans, which are integral to goal achievement and subsequent augmentation of self-efficacy (Bandura 1986), with many of those interviewed attributing to this skill their increased exercise activity. Participants' comments alluded to increased exercise self-efficacy as they referred to exercising more, to achieving 'a higher level of exercise' ('Simon' — pseudonyms have been used to preserve participants' confidentiality) and that exercise sessions 'gave me confidence to know that I could do it' ('Larry'). These observations suggest that quantitative measures alone do not fully explain the effect of interventions such as the CDSMP or supervised exercise on exercise self-efficacy, and point to a need to use qualitative methods of enquiry as well.

5.2.2.6 Self-Management Behaviours

Self-management behaviours did not alter significantly and effect sizes were small and comparable for both groups. Both groups reported what might be considered moderate self-management behaviours at baseline (6.1/8 for the intervention group and 6.2/8 for the controls). It is not possible to relate to published reference values, as

the Partners in Health tool does not appear to have been used as an outcome measurement of interventions before.

Following a programme designed to facilitate the development of self-management and which includes topics related to self-management behaviours, lack of significant improvement could be thought surprising. However, these participants have lived with COPD for a number of years. Those interviewed reported an average duration of six and a half years since diagnosis. As it may take many years until diagnosis (Bellamy, Booker & Fardy 2003), these people have been living with and adjusting to incremental impact on their health for often over a decade, developing self-management behaviours as a consequence. The findings in the following chapter support this explanation: participants revealed their self-developed self-management strategies in response to life with COPD.

5.2.2.6 Summary of Secondary Outcomes

In summary, the results of the secondary outcome analyses show that with or without supervised exercise of one hour per week, the CDSMP results in small improvements in physical function, role physical and role emotional domains of quality of life, exercise self-efficacy and self-management behaviours; and it facilitates the adoption of exercise. The addition of supervised exercise appears to assist individuals to undertake moderate exercise more frequently and for a longer duration. This increase in self-reported exercise is reflected in a greater effect on decreased breathlessness and increased physical component summary for the intervention group.

5.2.4 Recruitment and Attendance Patterns

5.2.4.1 Recruitment

Recruitment for the present population was by referrals received in nearly equal proportions from private respiratory specialists (and a small number of primary health practitioners), hospital ward personnel following a patient's discharge, and from outpatient specialist clinics. This is consistent with recruitment of recently reported studies in the cardiopulmonary rehabilitation literature (Finnerty et al. 2001; Gallefoss & Bakke 1999; Griffiths et al. 2000; Guell et al. 2000; Hui & Hewitt 2003; Man et al. 2004). However, the recruitment for the present study contrasts with that of much of the reported CDSMP research. Participants in these studies were mostly

self-referred volunteers, responding to media advertisements such as newspapers, radio, posters or brochures in doctors' waiting rooms or in senior centres, and personal invitations at outpatient clinics (Elzen et al. 2007; Farrell, Wicks & Martin 2004; Fu et al. 2003; Kennedy, Rogers & Crossley 2007; Lorig, Ritter et al. 2001; Lorig, Sobel et al. 1999; Swerissen et al. 2006). The only study to recruit participants directly from in-hospital referrals from health professionals was conducted in Hong Kong (Siu et al. 2007).

Studies recruiting self-referred volunteers attract criticism with respect to generalisation of results in that these people may have a higher level of self-management, evidenced by the fact they have sought out an intervention, and are therefore not representative of the general population. This points to the need for caution when comparing results of studies inviting self-referred participants with studies such as the present one. Referrals for my study were received from medical health professionals working in hospitals (state-run or public sector) or the community (private and public sector). As such, the recruited sample was representative of those who seek specialist medical attention; attend outpatient clinics or who have a hospital admission, indicating that they were less well than the general population with COPD. This may contribute to an explanation for the very small or negligible effect sizes seen in this study in many of the secondary outcomes for the CDSMP-only control group compared with the small improvements shown in the pooled results of CDSMP studies with mostly volunteer participants (Foster et al. 2007).

Referral Source and Socioeconomic Status

There was a significant difference between referral sources with respect to those attending a screening appointment and those not attending. Attendees were more likely to be referred by private specialists whereas non-attendees were more likely to have been referred by ward or clinic personnel. This difference was statistically significant. It could be argued that individuals seeking private specialist care and attending a screening appointment may be from a higher socioeconomic background. There was a slightly bigger proportion of people above the median of the index of relative socioeconomic advantage/disadvantage attending an appointment than not. However, there was no significant difference found between groups above or below

the median of this index. This index reflects income and workforce skill. For example, areas above the median have a higher proportion of people with a high income, high skilled workforce and lower proportion with a lower income and lower skilled workforce; and conversely for areas below the median (Australian Bureau of Statistics 2001). It seems unlikely that socioeconomic status influenced attendance at a screening appointment. These data suggest that the benefits of the programme may need to be emphasised by ward and clinic staff and patients encouraged to attend an initial assessment to discuss their needs and preferences.

These data indicate that the CDSMP study did not attract only people from a higher socioeconomic background. Although there was a larger proportion of individuals referred from the private sector, the largest proportions of participants and non-participants in the study were below the index of relative socioeconomic advantage/disadvantage. None of these differences were statistically significant.

Gender and Marital Status

Men and women, married or not, were represented in almost equal proportions in this study. Others have reported a higher proportion of females, with 75% in Australia (Nolte et al. 2007) and 70% from a review of lay-led self-management studies (Foster et al. 2007). As noted with referral source, the results of these analyses may reflect the volunteer-recruitment strategy of the studies. When participants were referred, there was no difference in the proportions of men and women enrolling. These results point to the need to explore a variety of recruitment strategies: those used to attract self-referred volunteers as well as referrals from medical personnel. As the findings in the following chapter will indicate, a doctor's recommendation is a powerful recruitment aid.

Patterns of attrition and reasons for non-attendance at screening appointments or non-participation in the study are discussed below. These considerations are integral to reaching as many people referred as possible.

5.2.4.2 Attendance Patterns and Reasons for Attrition

Reasons for Non-attendance or Non-Participation

Of 316 people referred over two years to the physiotherapy cardiopulmonary outpatient department for assessment, 30.1% did not attend a screening appointment,

and of those who did, 43.4% did not enrol in the study. These outcomes are consistent with recruitment proportions to other studies and programmes (Elzen et al. 2007; Griffiths et al. 2005; Griffiths et al. 2000; Ries et al. 1995; Stulbarg et al. 2002).

When the reasons for non-attendance or non-participation were examined, programme ‘unsuitability’ was cited by the greatest proportion of people. This is in contrast to Cockram et al. (2006) who cited poor health as the main reason for not enrolling in their programme. Being unwell applied to only a small number of people who chose not to participate in my study. Having other commitments (caring for grandchildren, attending medical or other appointments, going on holiday or work issues) were the most cited reasons for those choosing not to participate, and the fourth most cited explanation for non-attendance at appointments. ‘Unsuitability’ (not a group person, prefer to exercise at home, did not wish to commit, not interested in this programme and simply ‘unsuitable’ with no justification) was also a major barrier to study participation and the main explanation for not keeping a screening appointment. Travel issues did pose more of a barrier to enrolling in the programme than to attending initial screening appointments (11.0% versus 8.4%) but not nearly as big an issue as suggested by 56% of pulmonary rehabilitation coordinators who saw travel as the main barrier in Australia (Australian Lung Foundation 2007).

Reasons given for non-attendance at CDSMP sessions or supervised exercise sessions were similar. Being unwell was the major reason cited by participants for missing a session, an observation reported by two other Australian studies involving people with COPD (Cockram, Cecins & Jenkins 2006; Elliott et al. 2004) and by an English study of the CDSMP (Bancroft, Barlow & Turner 2004). People with COPD experience repeated exacerbations of their condition (Bellamy, Booker & Fardy 2003; MacNee & Rennard 2004), so it is not surprising that this should emerge as a main reason for non-attendance at programmes. Therefore, participants should be given opportunity to ‘make up’ the missed sessions, to repeat the programme, or have discussions as to whether or not needs have been met, and if not, a course of action collaboratively determined to meet those needs.

These results suggest enquiry about the reasons for non-attendance or non-participation should be made in order to provide a service that considers the needs and preferences of the individual. These data clearly indicate that one approach does not suit all those referred. There are those for whom centre-based interventions are not suitable or practical. To extend the reach of chronic disease self-management and exercise interventions, a range of options needs to be offered. In this way we may be able to reach the two-thirds of those people with moderate to severe COPD who are referred and who do not wish to, or are unable to, attend centralised group-based programmes.

CDSMP and Supervised Exercise Attendance Rates

The median attendance at the CDSMP and supervised exercise was five sessions. Attendances on any one occasion were slightly higher at supervised exercise than the CDSMP (70.7% versus 65.5%). Participants were observed to attend the supervised exercise even if they could not attend the CDSMP, or vice versa, usually due to conflicting appointments.

The attendance data for the CDSMP reported here compares favourably with a recently reported Australian study (Swerissen et al. 2006). The people from culturally and diverse linguistic backgrounds in that study also attended five out of the six sessions. The population in my study was primarily English-speaking and identified themselves as being of Australian nationality. This study adds to the attendance data for the CDSMP in Australia, and is encouraging in that once individuals enrol in the CDSMP, the majority complete at least five sessions.

Attrition of 17.9% of people randomised in this study was similar to that of other studies reporting baseline and immediately post intervention rates in the cardiopulmonary rehabilitation literature (Carrieri-Kohlman et al. 1996; Griffiths et al. 2000; Hui & Hewitt 2003; Man et al. 2004). It is difficult to draw comparisons with the CDSMP studies as post-intervention outcomes were usually measured at four or six months, and were by mailed-back questionnaires. Nevertheless, lost to follow-up was reported as 17% in the initial CDSMP study at Stanford University (Lorig, Sobel et al. 1999) and 18.3% in a Chinese study (Fu et al. 2003), comparable to my study. Interestingly, participants in Hong Kong had a low attrition rate of 7.5%

(Siu et al. 2007), which may reflect cultural differences, age or a higher level of participants' health.

The 15 participants who did not complete post programme data in this investigation did not differ significantly to those who completed the study with respect to gender, age or marital status. There were insufficient data to report significance for referral source or COPD grade, but the data suggest that proportions in both groups were similar. This is an important consideration as it could be assumed that those who do not complete a study may be more unwell, older or have no partner, thus introducing bias into the data collected. This was not the case, suggesting that those who completed post-intervention outcomes were representative of the sample as a whole.

5.3 *Quantitative Study Limitations*

There were limitations to this study. First, participants were recruited from individuals with COPD referred to the physiotherapy outpatients department at a metropolitan hospital. Participants were also more likely to have severe COPD. They may differ from others in the community or from those who self-refer to programmes, and from those with mild COPD. As such, caution would need to be exercised before generalising these results to other populations with COPD.

Secondly, a major limitation was placed upon the study by the facility resources. As the study had to be incorporated into existing clinical practice, no more than seven participants could be allocated to the gym for supervised exercise. Thus randomisation had the potential to be compromised. However, there were no significant differences between the intervention and control groups at baseline. After adjusting for the possible confounders of age, education, breathlessness and baseline exercise level there was no need to doubt the unadjusted results. It is unlikely that randomisation was compromised.

Thirdly, as we were limited to when we could offer the self-management programme, we were unable to offer two separate groups for the CDSMP. Therefore, participants who were randomised to the supervised exercise intervention attended the CDSMP with the control group. Care was taken to avoid the effect of disclosure, and participants respected the request not to discuss the exercise experience. However, the effect that the achievements of the intervention (supervised exercise)

group may have vicariously had on the control group could not be isolated. Nevertheless, as the qualitative findings showed, participants like 'Carol' (control) were motivated to exercise by the achievements of others who did not attend supervised exercise.

Fourthly, a further resource limitation concerned the necessity of using existing staff. Hence the CDSMP was facilitated by the two trained health professionals who usually fulfilled this role. One of the leaders was the investigator. Thus there may have been an element of participants giving a socially desirable response to the questionnaires. However, the investigator did not administer any of the outcome measures, and reinforced to participants the importance of their frank answers, hence minimising potential bias.

Fifthly, as noted above, the leaders were health professionals. However, both could also be identified as peers with chronic conditions. While participants saw this as a strength of the programme, outcomes may have been different if the programme was facilitated by non-health professional peers for this condition-specific group of people. A recently published systematic review concluded from three studies that there were few differences between peer-led or health professional-led self-management programmes (Foster et al. 2007). Therefore, there is no reason to believe that outcomes of this study would be different if led by non-health professionals.

Despite these limitations, this study has shown that it is possible to conduct rigorous research within an existing facility, using existing resources and personnel. By doing this, the results are immediately transferrable to existing clinical practice.

5.4 Chapter Summary

This discussion highlights six main points.

First, to affect a statistically significant increase in physical capacity, one hour of supervised exercise does not have to be an integral component of the CDSMP. With or without supervised exercise, participants with COPD can expect a small equivalent increase in their physical capacity. The most likely explanation for this is the behavioural basis of the CDSMP to which all participants were exposed,

facilitating self-regulation of exercise, suggesting increased personal control.

However, clinical significance was not reached. Further research as to what a small change in physical capacity means to people already compromised by COPD is a much needed area of future enquiry.

Second, low frequency of exercise sessions could partially explain the small increase in distance walked. Multiple linear regression analysis showed those who exercised less frequently and had higher self-efficacy for exercise experienced a greater change in 6MWT distance. This points to the advisability of addressing these variables when individuals present at rehabilitation or self-management programmes with improved physical capacity as one of the aims.

Third, secondary outcome analyses show that with or without supervised exercise, participants with COPD can expect small, non-statistically significant improvements in:

- physical function, role physical and role emotional domains of quality of life
- exercise self-efficacy
- self-management behaviours
- facilitation of exercise adoption.

Fourth, the addition of supervised exercise to the CDSMP gave additional small benefits in:

- increased frequency and duration of self-reported moderate exercise
- decreased breathlessness
- increased physical component summary of the SF-36v2.

However, with the exception of duration of moderate self-reported exercise, statistical significance was not reached. Therefore, the pre-test post-test improvement does not by itself provide evidence of the efficacy of the intervention. Further research is required in this area.

Fifth, recruitment and attendance rates reflect that of other studies in cardiopulmonary rehabilitation and the CDSMP arena. The major reason cited for non-enrolment was programme 'unsuitability', and for non-attendance at the CDSMP or supervised exercise was being unwell. These factors deserve

consideration and a flexible ‘menu’ of interventions offered to extend the reach of interventions.

Sixth, the qualitative findings have been referred to in the above discussion. They point to the need to listen to participants’ voices, which at times both support and contradict the quantitative data. These findings will be presented in the following chapter, *Chapter Six*, and discussed in *Chapter Seven*.

6

CHAPTER SIX:

QUALITATIVE RESEARCH FINDINGS

6.1 Introduction

This chapter will explore the findings from the 14 men and six women interviewed in the qualitative component of the study. These data were analysed prior to completion of the quantitative data collection and its analysis. While this was not the original intention, time constraints dictated that I do so and resulted in an unintended positive consequence. By analysing the qualitative data first, I have in no way been influenced by the evaluation of quantitative outcomes.

As discussed in *Chapter Three*, the research sought to inform the clinical dilemma of whether or not to combine supervised exercise with the CDSMP. To answer this query, the research was approached using quantitative and qualitative methods. A mixed methodology is important to this research because it will provide a strong objective evidence base for the effect of supervised exercise with the CDSMP. Additionally, it provides insight into what participants perceived as important to them, and what factors influence the best possible health behaviour change. The governing qualitative questions were:

What is the lived experience of people with COPD who attend the CDSMP with or without supervised exercise (CDSMP±Exercise)?

and

What implications does this have for clinical practice, in particular, for offering supervised exercise or not with the CDSMP?

These questions are important because they will assist health professionals in gaining an understanding of the CDSMP with or without supervised exercise from the

perspective of the person with COPD. By ascertaining what is important to that individual, health professionals will be better situated to work *with* the person with COPD, rather than focusing solely on what the health professional perceives as important. In this way, clinical interventions such as the CDSMP or supervised exercise may be better tailored to the needs and preferences of those for whom they are offered.

The data presented in this chapter enable and support the above endeavour. From the qualitative analysis themes and sub-themes emerged and were developed into three broad categories. I will present descriptions of these and highlight the interconnections in presenting the findings in the following sections. I have depicted the categories with themes and sub-themes in Table 34.

Table 34: Findings: Categories, Themes and Sub-themes

Categories	Themes	Sub-themes
Living with COPD	Meaning of COPD	Loss of physical capacity and emotional harmony Loss of expectations Loss of gendered (masculine) roles Loss of independence
	Self-developed Strategies: Utilising Internal Resources	Planning and pacing activities Acceptance of limitations
A Personal Meaning of Self-management	Self-management Activities	Following medication regime Exercise and have a healthy diet Maintain a sense of independence
	Self-referent Concepts	Self-Awareness Acceptance Self-Reliance
A 'Shared' Engagement	Presenting and Participating	Doctor's recommendation Helping and Learning Commitment: a source of internal motivation Commitment: a source of external motivation
	The Power of more than One: Social Benefits	Relief from social isolation Peers: a source of motivation and learning Peers: a source of identification Social comparison
	A Self-Focus	Self-consideration Self-regulation during supervised exercise
	Facilitating Engagement	Participant-engagement and supervised exercise Participant-engagement and the CDSMP

Prior to exploring the participant experience of the CDSMP with or without supervised exercise, I gathered data from semi-structured interviews about living with COPD for these people in order to contextualise their stories. Participants spoke of the overwhelming effect of living with breathlessness, a cardinal symptom and feature of life with COPD (Bailey 2004; Bellamy, Booker & Fardy 2003) and ensuing losses, which I will describe in the first theme. What the data will show is that the impact of COPD was so profound that it became the explanation for these participants (Nettleton et al. 2005), constituting the first theme of this category, *'Meaning of COPD'*. This is illustrated in Figure 10.

As the following participants' comments will reveal, life with COPD can be difficult, and a challenge to which these participants responded by developing their own strategies for coping. This emerging theme, *'Self-developed Strategies'*, demonstrated that people bring these strategies, their personal attributes and the meaning of life with COPD to healthcare interactions, as shown in Figure 11. They present as a total person with skills and strategies, and not a blank canvas that needs to absorb 'self-management', as some of the literature seems to imply (Fu et al. 2003). The interplay of the self-developed strategies with the meaning of COPD is depicted in Figure 12. These two themes formed the first category, *'Living with COPD'*.

These prior experiences and that of the CDSMP with or without supervised exercise served to mould a meaning of self-management for the participants. These findings are presented in the second category, *'A Personal Meaning of Self-management'*. Two themes, *'Self-management Activities'* and *'Self-referent Concepts'* emerged from the data in this category and are depicted in Figure 13.

As I considered the experience of the CDSMP with or without supervised exercise, these data suggested to me that there were similar motivational influences serving to encourage participants to continue both the CDSMP and supervised exercise. Parallel motivational influences acted across the CDSMP and the supervised exercise sessions, forming the third category's first of two themes, *'Presenting and Participating'* as illustrated in Figure 14. *'The Power of More Than One: Social Benefits'* (relief from social isolation, influence of peers and social comparison) surrounding the experience of the CDSMP and exercise emerged from the data as

important to participants and constituted the second theme. These data pointed to a third theme, '*A Self-Focus*', which will be elaborated upon later in this chapter. The benefits and processes of experiencing the CDSMP±Exercise are depicted in Figure 15. In addition, participants' descriptions of their experiences pointed to a preference for guidance, rather than following a prescribed regime, and respect for their choices, rather than being told what to do — elements that were not emphasised in their experiences of more traditional approaches. This suggested a fourth theme, '*A Facilitating Engagement*', shown in Figure 16. Together these themes formed the third category, '*A Shared Engagement*'.

As well as the above observations, these data suggest a framework that draws together a meaning of life with COPD, self-management and social processes derived from group participation, reinforcing the construct of self-efficacy and personal control. These data lead to conclusions that this framework provides the common link between the experience of supervised exercise and the CDSMP. It reinforces the necessity of listening to the participants' voices. I will develop this concept further in the following chapter.

6.2 Research Findings

I will illustrate the findings with vignettes and quotes to personalise the data and to contextualise the participant experience (Hansen 2006). The data are linked with pseudonyms to preserve confidentiality and I have not linked these with the demographic data in *Chapter Four* for this reason. Where there may be identifying data, an 'X' or similar letter is used, or I have not reported that information and this is noted in the text.

As the findings will reveal, the programme impacted on people's lives in a similar way, irrespective of whether or not supervised exercise was attended. Participant comments suggested that most benefitted from the experience whether they were in the intervention or control group. To help illustrate this, I have indicated in the text whether a participant attended the CDSMP with supervised exercise or without, by placing 'I' (intervention group) or 'C' (control group) respectively in parentheses after the participant's name relating to a quotation.

In the first category, I will outline the meaning of COPD for these participants, using their descriptions as illustration. These data contextualise the managing strategies participants developed and brought with them to their interaction with the CDSMP with or without supervised exercise.

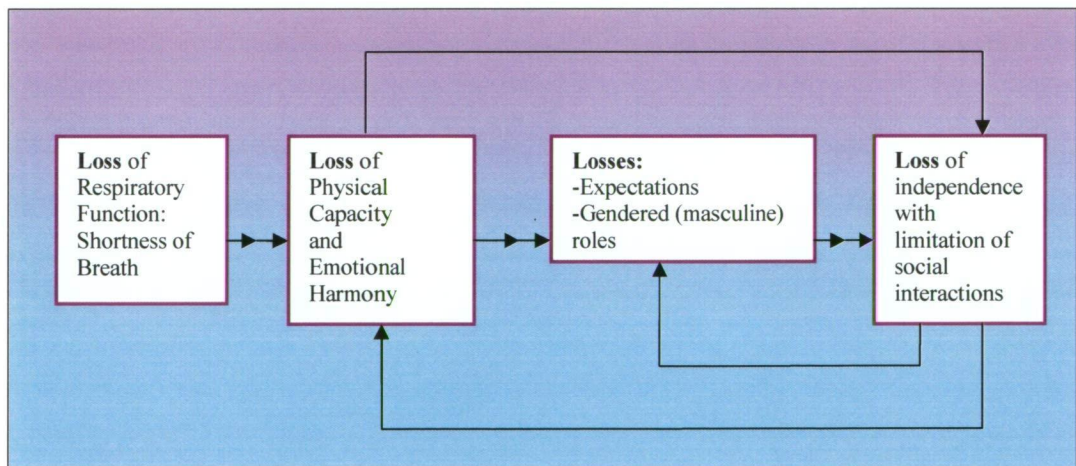
6.2.1 Living with COPD

As mentioned previously, for many participants, the meaning of COPD was described in terms of its impact. Participants reacted by developing their own strategies, a response to living with chronic conditions reported by others (Corbin & Strauss 1988). These data are presented below.

6.2.1.1 Meaning of COPD

The meaning of COPD ascribed by these participants was one of losses, precipitated by the loss of respiratory function. The findings will show that eroding physical capacity, defined in *Chapter Three* as the ability to carry out the tasks of everyday life (Guyatt et al. 1985), with accompanying stressful emotions caused a cascade of other losses: loss of expectations, of gendered masculine roles and of independence as shown in Figure 10.

Figure 10: Meaning of COPD



Decreased physical capacity may have directly resulted in restricted social interactions and a loss of independence, or, as the data reveals, social restrictions may have been self-imposed to avoid the stigma of unwanted attention. In this way, participants experienced losses in their lives that were dictated by their physical and social limitations, echoing the findings of others (Charmaz 1983; Mathieson & Stam

1995). In turn, this reinforced the spectrum of losses, further eroding physical capacity and emotional harmony. The interplay of symptoms and experiences that contributed to the meaning of COPD for the participants is diagrammatically represented in Figure 10 above.

Loss of Physical Capacity and Emotional Harmony

Eroding physical capacity intertwined with ensuing stressful emotions provided a link between other sub-themes. Therefore I have presented data contributing to this sub-theme first. In the following vignette Gary (I) explains the loss of physical activities and ensuing emotional response, echoing the stories of other participants.

Gary lived alone in a one bedroom flat. He had left his front door open, to enable me to walk straight into his home so that he did not have to move from his table. As I walked into Gary's living room, I noticed he had everything he needed within easy reach: his glass of water sat next to his computer; a box of chocolates was next to that. The telephone vied for space amid a jumble of books, letters and pens. His oxygen cylinder sat beside him. A chest of drawers into which he could delve by simply swivelling around in his chair was behind him. He indicated a chair, squeezed between a cabinet and his wheelchair, and suggested I dust that off and sit there. He began to tell me about life with COPD:

Helen: 'What is it like for you living with a chronic condition...how would you describe your chronic condition?'

Gary: 'Frustrating is the worst thing I think, because *I can't do what I want to do*. Coming to terms with that is the hard part. It's very annoying that you can't do all of these things and it goes on then through the whole series of anger, and all of those things, every time you think about your situation, you get angry, you get frustrated, you get annoyed, you get worried, and then of course, you can get into depression and so on'. [emphasis added]

Like Gary, other participants spoke of experiencing a cluster of negative emotions pointing to the risk of developing depression. This is not surprising when a 42% prevalence rate of clinical depression has been reported in elderly outpatients with COPD, a group similar to the participants in this study (Yohannes, Baldwin & Connolly 2000). While I acknowledge that many people experience stressful emotions during their lives, this seemed to be magnified for these participants living with COPD, particularly when physical ability became progressively curtailed as the disease progressed. This led to an array of emotional responses, especially as participants were required to adjust to losses of varying kinds, as the following findings reveal.

Loss of Expectations

Participants expressed disappointment, unresolved frustration and undermining of self-perception for being unable to do things they might reasonably have expected to do. Bury (1982 p. 169) refers to this loss of expectations as a disruption of 'taken-for-granted assumptions and behaviours'. Such responses were compounded by the variable nature of the symptoms of COPD. Barry (C) explained:

'Some days it's worse than others. The day before yesterday we trimmed that big bush out the front, and we managed that, but other days, other times I can't do things like that...I can see myself as a failure...Well, I have already explained that I can't do things. I can't visit. There's [sic] lots of things I can't do. That makes me feel inadequate'.

As well as loss of day-to-day expectations, participants also referred to unrealised futures, or what has been termed an altered trajectory (Corbin & Strauss 1987) to the paths they had expected their lives to follow. Some ceased employment prematurely. Gary (I) was a shop-owner, others did not undertake intended travel, either locally (Chris [C] and Barry [C]), or 'a world tour, but I couldn't do it now' (Ewan [I]). One had to move to a more manageable dwelling (Nancy [C]).

Loss of Gendered (Masculine) Roles

The majority of men in this sample referred to a loss of their gendered roles and expectations. The women in this sample did not refer to losses in this way. Gendered roles are considered to be attitudes, behaviours and values, influenced by the society in which one lives and that are considered appropriate for men and women (Corrigan & Konrad 2006). For some men in particular, their assumptions of their gendered roles in their family units as being responsible for heavy tasks were challenged by the symptoms of COPD as their ability to physically do these tasks declined. As Mark (I) told me:

'She [his granddaughter] said, "Anytime you want the lawn mowed, just ring me". But there again I hate imposing on them. I should be doing things for them not them doing things for me...I still find that I am calling on my son more and more every week, probably, to do things that I should be doing myself. It doesn't do much for your self-esteem because you feel so damn useless'.

Mark seemed to speak for these men. His comments suggest that accompanying these losses was a need to rely on help from others, compounding feelings of worthlessness, suggesting a loss of self (Charmaz 1983).

Loss of Independence

The above comments suggest to me that as the participants' independence was challenged they perceived themselves to be devalued or discredited and not the whole or 'normal' person they had perceived themselves as being. Loss of independence, resulting from their chronic condition, caused these participants to feel the stigma of being less of a person, one who did not meet the expectations imposed by society and themselves (Goffman 1968). The notion of independence reflects a major value-system of what is considered 'normal' and acceptable in Australian society (Walker et al. 2003). Some responded by self-labelling, as Max's (C) statement reveals:

'Well, thinking about what I used to do, you think that you are lazy'.

Others voluntarily curtailed activities to avoid unwanted attention from, and feelings of embarrassment in front of others. Chris's (C) comments highlight this:

'I'll go and just sit and watch, but it doesn't do me any good, because inside you feel like you are fit enough...and then you are going to make yourself feel inadequate as far as the other people around you are concerned, it just makes it so hard'.

These participants appeared to me to take steps to avoid internal feelings of shame and worthlessness, whether or not others reacted negatively to them. That is, by taking steps to avoid perceived 'enacted' stigmatising behaviour toward themselves participants experienced what the literature refers to as 'felt' stigma (Scambler & Hopkins 1986), undergoing a process referred to as 'internalisation' of stigma (Walker et al. 2003).

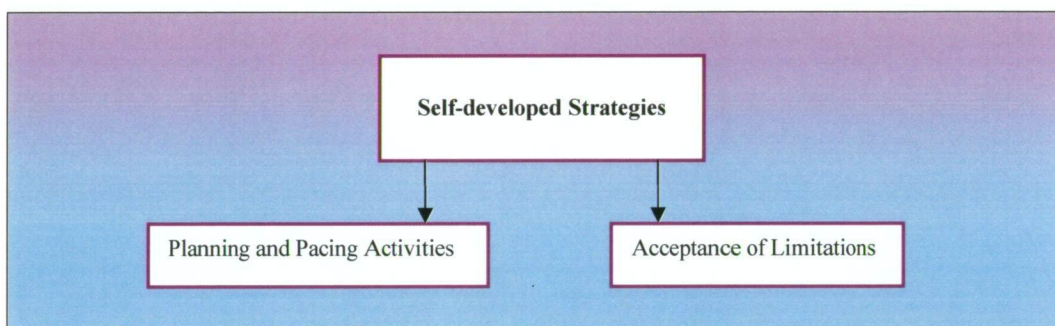
The foregoing theme of the meaning of COPD for these participants provides the framework from which these individuals developed strategies as they managed their lives with COPD, as the following theme will illustrate.

6.2.1.2 Self-Developed Strategies

As the participants spoke with me, I glimpsed their hopes and fears, their attributes and attitudes, as well as the array of strategies they have consciously or subconsciously developed in the course of life with a chronic condition. The self-developed strategies were in response to a life circumscribed by the consequences of their COPD (Bury 1982), and people brought these strategies with them to the

programme. Managing the impact of life with chronic conditions is referred to by Bury (1982) as ‘mobilising resources’. Other authors have referred to this process as ‘getting in harmony with oneself’ (Delmar et al. 2005), ‘development’ (Yoshida 1993), ‘accommodation’ (Radley & Green 1987), or different types of ‘work’ — illness trajectory work, everyday life work or biographical work (Corbin & Strauss 1987). The strategies the participants described as they mobilised their resources to accommodate their COPD form the second theme of this category and are represented in Figure 11.

Figure 11: Self-developed Strategies



The theme, ‘*Self-developed strategies*’ carries with it a positive connotation. These data indicate that the strategies these participants referred to were developed as a positive adaptation to the impact of living with COPD (Bury 1991; Williams 2000). It must be remembered that participants spoke with me after attending the CDSMP. Therefore their strategies may have been influenced by this experience. However, when asked where this had been learnt, participants pointed to life with COPD prior to attendance at the CDSMP. This is illustrated by the quotations from participants below.

Two sub-themes emerged, as shown in Figure 11. Planning and pacing activities and acceptance of limitations were the major self-developed self-managing strategies these participants brought with them to the CDSMP with or without supervised exercise, as the following findings will reveal.

Planning and Pacing Activities

Planning and pacing activities was a self-developed strategy implemented by these participants as a positive approach to accommodating the impact of COPD on their daily lives, lessening the impact of breathlessness on their ability to accomplish

physical activities of life. This process has similarly been described as ‘routing’ (Fagerhaugh 1993), although this is not a term commonly used in Australian physiotherapy practice. As a physiotherapist, I am familiar with helping people with COPD practice pacing or staging activities, such as stair climbing, walking, rising from a chair or a bed while maintaining an efficient breathing pattern. I was therefore most interested to hear what people actually do to plan and pace the daily activities of their lives, and how they had arrived at these decisions. The following vignette illustrates this.

Ben (I) sat at the table with me. He lent forward and began an explanation of the health crises he had experienced during his life. Despite recent cardiac problems, the breathlessness he experienced from his COPD exerted by far the greatest impact in terms of physical activity limitations. He had developed his own strategies for managing his life with this restriction.

Helen: ‘So how do you live with that?’

Ben: ‘You learn to control what you can do. You get wise. You know that if you walk up a set of stairs you are going to get out of breath. So you walk up half the stairs, or you wait and catch a lift up one flight, where once you used to run up the stairs. You make two trips to the shop instead of coming home laden with parcels [planning]. You know what your limits are and you don’t exceed them. So what I have learnt to do is to control my activities to what my breathing is. I have just had to slow down and just do things I can do’. [pacing]

Helen: ‘How did you go about learning that?’

Ben: ‘I used to do things and I would get that puffed I could hardly breathe. I would be get so puffed out I would almost pass out...the body couldn’t cope with what I wanted to do...It’s like a convoy of ships. You can only go as fast as the slowest one, so that’s what it is, otherwise they would be spread out all over the ocean. I have just learnt that my lungs are slower than my brain is, so I just have to slow the rest of me down to the speed that my lungs can go at.’

Chris (C) described how he had to pace himself and

‘... sit on the side of the bath when I get out and get my breath before I can dry myself, and that in itself is a chore, because I get very short of breath. I do it in stages. I dry my back, then sit, then continue on and do the rest, and powder etc’.

He told me he was not told what to do,

‘... but naturally when you have a condition like chronic emphysema [COPD], you do that sort of thing, because you know that you have to do it and you have to pace yourself to get the job done’.

Dan (I) was clearing some land and managed this by ‘chopping it into smaller bits so that I don’t have all of it in one big lump, finding something lighter to do for the

other half of the day'. Peter's (C) 'passion' was gardening. He outlined his planning and pacing strategy, saying:

'Generally I know what I can do and what I can't do, and I generally have to pace myself and virtually decide if I'm going to do a bit of gardening, what I'm going to do and how long I will do it for and try and stick to that and then go and have a sit or move to another area of the garden and admire the flowers there whilst I prepare myself to have another go'.

While some participants denied planning ahead because of the variable nature of COPD symptoms, in reality they planned according to how they felt 'on the day', noting that 'by the time you are out of bed and having your cup of tea, you know what the day is going to be like so you plan accordingly' (Sally [C]). Nigel (I), who loved to cook, indicated that he planned his shopping. If he could 'only get half way around the supermarket' he indicated he had to plan 'to come back another time and do the rest.'

Acceptance of Limitations

Acceptance of their limitations was a strategy that appeared to be part of a conscious attempt to explain the losses accompanying COPD, which I described earlier in this chapter. The tempering of age and acceptance that abilities decline as part of the 'normal' ageing process (Williams 2000) and that older people have developed skills to adjust to life's demands (Pound, Gompertz & Ebrahim 1998) is in keeping with a 'biographically anticipated' view of life (Lawton 2003). Perhaps the comments from some participants in this study also reveal an optimistic disposition that has been linked to managing stressful events or negative emotions (Nes & Segerstrom 2006). Accepting the ongoing nature of COPD and explaining this as an expected partner to ageing or as something that cannot be changed, appeared to be an example of marshalling internal optimistic resources to deal with a potentially stressful situation, and so interrupt a circuit of losses. Simon (C) explained:

'When you get to this sort of age [76 years] I have no trouble accepting that you have really had your innings and we are all going the same way, if you get the short straw and pull out a bit earlier...I suppose it [COPD] brings it home to you, the finite nature of life. When you are young life stretches before you forever and anything is possible. Your productivity comes down and down... as you get on...you are satisfied with less in the way of achievements'.

Age was not always invoked as an explanation for the consequences of COPD. An acceptance of problems that cannot be changed, and resourcefulness in dealing with those that can be changed is revealed by the following participants. Max (C) said:

‘I have adjusted myself. Everything affects you, but you just have to sit down and talk to yourself and say “that’s happened and can’t be undone”, and life goes on’.

Max’s acceptance of his limitations evidenced itself in his readdressing an initial resistance to seek help. Instead of representing a source of threat to his independence and a potential source of stigma as I suggested earlier, seeking help became a resource or a strategy by which a valued sense of self could be maintained. He noted his earlier resistance to accepting help and gendered expectations of roles, adding

‘but that’s changed, we [his wife and he] work as a team, we work together, we go out and do the garden together...things like that, that I thought were sissy jobs before’.

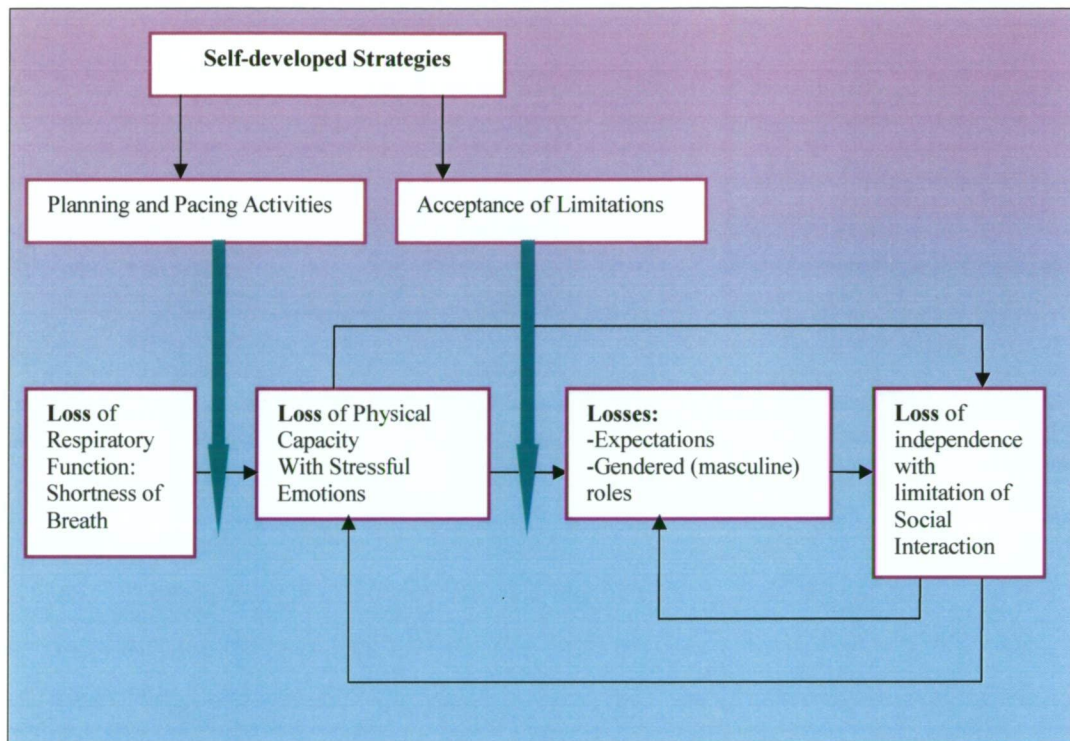
Others indicated that acceptance of physical limitations need not mean a negative approach to life. Barry (C) described ‘pottering around’ at an adjusted activity level, which he perceived as exercise, matched to the degree of breathlessness on the day. Ben (I) commented that he was ‘70%, happy with what I am...and if that is as good as you’re ever going to be, well that’s as good as you’re ever going to be.’ Ewan (I) acknowledged that having COPD did impose limitations, but ‘it is not something I get all upset about’. Simon (C) demonstrated problem-solving and resourcefulness as he accepted and adjusted to the restrictions COPD was imposing on his life. He said:

‘...I want to be able to enjoy the things I like doing. Not necessarily the things I have enjoyed in my past life, because highly active things disappear from the menu...I will make use of that time one way or another and I will enjoy myself...So a little bit of disappointment of course, but it is only mild. I think it is all related to the things you like doing. If I can’t do bicycling then I have no problems finding other things to do equally satisfying or more satisfying.’

Accepting the ‘chronicity’ of COPD seemed to enable these people to view it as a future partner to their lives. Max (C) noted that he accepted ‘that it’s long term and I’m not going to come right. That’s a big difference’. Larry (I) observed:

‘...I am not going to improve, so I guess it’s a matter of one has to resign oneself to the fact that you have a problem. You are not going to get any better, so you have to try to make the best of it’.

These data suggest to me an adjustment to COPD wherein symptoms were accommodated within the social context of the person’s life (Radley & Green 1987).

Figure 12: Living with COPD

In addition, these data reveal some of the self-management strategies people bring with them to healthcare interactions. The participants' strategies interrupted the symptoms and limitations imposed by COPD on their lives, acting as a 'circuit breaker', as represented in Figure 12 above.

In summary, participants developed their own self-management strategies to deal with the profound impact that breathlessness from loss of respiratory function had on their lives. These strategies interrupted the shortness of breath-loss and limitation cycle that served as the meaning of COPD for these individuals. Their strategies assisted them in accommodating the effect of COPD on their lives.

The foregoing category contextualises the following themes that emerged from the data as I sought to understand the meaning of self-management and the experience of the CDSMP with or without supervised exercise for these participants. These data formed the next two categories.

6.2.2 A Personal Meaning of 'Self-Management'

I did not interview participants prior to attending the CDSMP, so it is not possible to isolate the influence of their prior experiences from that of the CDSMP when

considering what meaning they would ascribe to self-management. Following a review of the literature (*Chapter Two*), I suggested a definition of self-management.

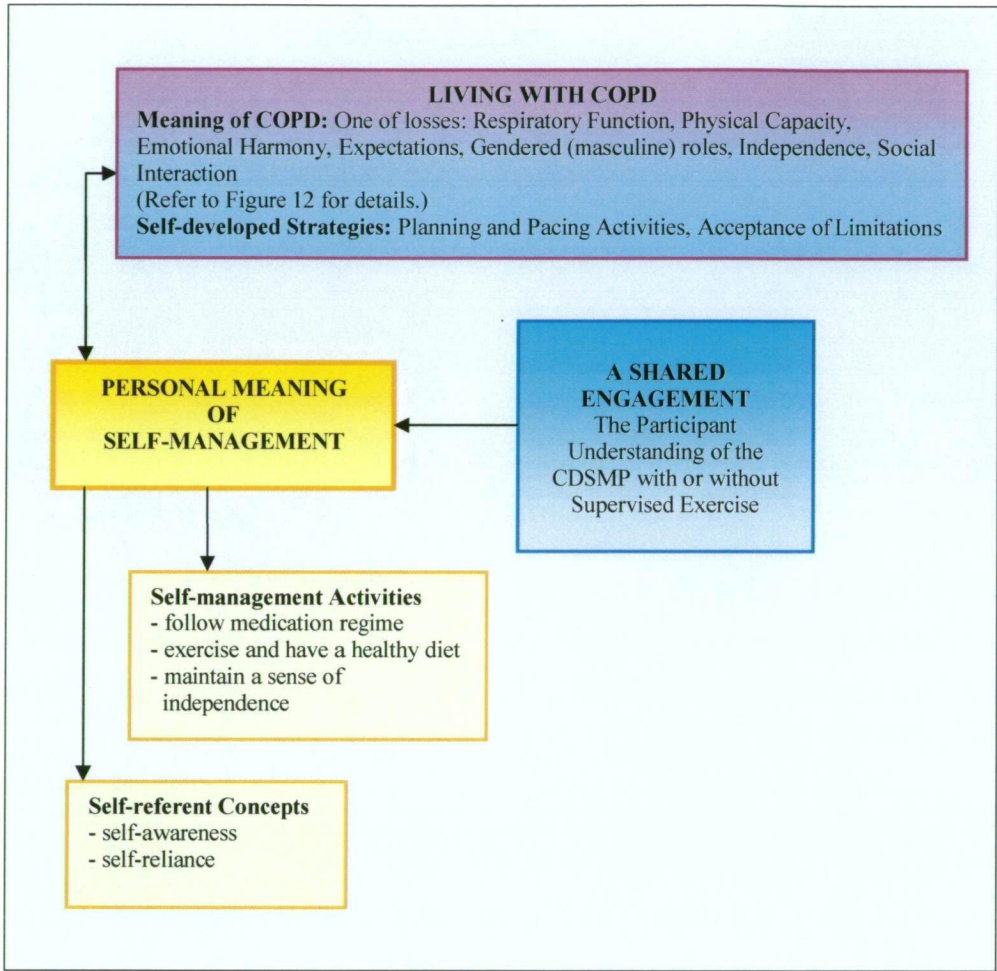
To reiterate, self-management is a dynamic process incorporating an individual's capability and confidence to undertake responsibilities and to engage in activities that enable them to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and their medical, emotional and social domains.

The literature suggests that to be an effective self-manager, individuals should engage in prioritising, planning and pacing; following a symptom action plan; seeking and implementing health-related information; having effective communication and decision-making skills and working with carers and healthcare providers in order to problem solve and develop action plans to achieve goals (Battersby et al. 2003; Clark et al. 1991; Corbin & Strauss 1988; Lorig & Holman 2003).

As the data revealed in the previous category, '*Living with COPD*', bodily symptoms had such an impact that they were invoked by participants in defining the meaning of COPD. Similarly, I noticed that in ascribing a meaning to self-management, the participants drew upon activities they saw as necessary to manage the impact of COPD on their lives. Thus, life with COPD influenced a meaning of self-management that in turn *enabled* that life with COPD. The experience of attending the CDSMP with or without supervised exercise also influenced the meaning of self-management for participants. This concept is depicted in Figure 13 below.

Also described in the previous category were planning and pacing activities and acceptance of limitations — major self-managing strategies developed prior to attending the CDSMP with or without supervised exercise and to which participants had referred when describing life with COPD. These are differentiated from the self-management activities and self-referent concepts contributing to a meaning of self-management presented here. These data suggest to me that the strategies referred to previously provide a means of undertaking self-management activities and allowing a focus on the self to occur.

Figure 13: Personal Meaning of Self-Management



In presenting the following findings, I will draw comparisons with the extant literature and offer additional insights from the participant perspective, noting where participants indicate the influence of the CDSMP.

6.2.2.1 Self-Management Activities

Not surprisingly for people with a condition having a profound impact on their health, for many of these participants self-management meant adopting or maintaining health-related behaviours, an activity observed by others for people with chronic conditions (Clark et al. 1991; Corbin & Strauss 1988). Such engagement with activities has been conceptualised as a task (Lorig & Holman 2003) or included in an operationalised definition of self-management (Battersby et al. 2003). The participant-identified self-management activities are presented below.

Following Medication Regime

Following a medication regime has been reported by others as a common behaviour for people with COPD (Silverman et al. 1999). Barry (C) indicated that ‘You manage your own sprays and puffers and what tablets you have to take’ Max (C) supported this statement:

‘Self-management means managing your condition, learning to cope with it, how to know your medications, how to use your medications properly to get the best results.’

Exercise and a Healthy Diet

Undertaking exercise and ensuring a healthy diet were also nominated health behaviours. Ewan (I) saw self-management in terms of physical activity when he told me that ‘the main thing is to keep up my physical ability or what there is of it’. Len (I) and Nancy (C) included being ‘fit’ and following a healthy diet in their understanding of self-management.

For Mark (I), self-management meant ‘there is an easy way to do things and a hard way to do things’. The strategy he employed to make managing ‘easier’ was prioritising. With ‘a son in a wheelchair’, he needed to quarantine time for himself to achieve his exercise goals, which he identified as a self-management activity. He explained:

‘My exercise . . . if I am coming in here [to the physiotherapy gym] I ring him [my son] up and tell him I won’t be coming around tomorrow and he knows that.’

Donald (I) had withdrawn from the programme after one session. He included exercise and modifying his diet in his definition of self-management, indicating an awareness of health-related behaviours held independently of the CDSMP or exercise sessions. He indicated that behaviour change is a difficult endeavour and may occur incrementally. He said:

‘If I was to have more exercise...I don’t think that I eat a lot, and I have tried to change my dietary habits. Pie and chips are now once a week instead of five times a week...’.

In order to maintain health behaviours, Barry (C) spoke of ‘self-tailoring’, supporting Mark’s (I) comments of finding an ‘easy way’. He said:

‘I have to work out what is best for me... you work out what you can do the easiest way and that’s it. That is self-management’.

'Self-tailoring' is a term used by Kate Lorig and colleagues (Lorig & Holman 2003) in their discussions of self-management. By employing self-tailoring, participants' comments suggest that managing daily activities was facilitated. Although participants did not allude to the self-developed strategies of planning and pacing activities described in the previous category, this is nevertheless a self-management activity whereby participants tailored their level of exertion to enable activities to be completed.

Maintain a Sense of Independence

Loss of independence was described previously as a sequel to life with COPD.

Maintaining a sense of independence was invoked by participants in a meaning of self-management. Mary (I) saw self-management as maintaining independence in her daily activities. She explained:

'It means to me that I can do for myself...I'm not talking about fixing a lawn mower or things like that. I'm talking about everyday things, being able to clean myself, clean your clothes, clean your house, cook for yourself, the normal everyday things like that. That's what self-management means to me, and being able to do it in an orderly fashion'.

In keeping with most men in this sample, Gary (I) also viewed seeking help in a negative way. However, by being the orchestrator of the assistance required, it appeared to me that Gary was maintaining a sense of independence in his life. His comments also infer a sense of personal control as being an element of maintaining a sense of independence, and this will be discussed in the following chapter. In his meaning of self-management, he rationalised:

'...you have to learn to delegate...You manage yourself by these compromises. You find ways around them that is not going to be too much of an impost on people.'

Gary's comments suggest to me that he was aware of the limitations COPD placed on his life, echoing the voices of people with arthritis in another study (Kralik et al. 2004). I will discuss self-awareness in the following theme.

6.2.2.2 Self-referent Concepts

Participants' comments pointed to reference to the self, in terms of self-awareness and self-reliance. As discussed in the previous category, acceptance of limitations emerged as a self-developed strategy participants utilised for living with COPD. However, it was not until they were specifically asked about their meaning of self-

management that the data revealed self-referent concepts such as self-awareness and self-reliance, both of which appear to me to be an important step in acceptance of life with COPD. These data are presented below.

Self-awareness

Chris's (C) comments suggest to me the importance of self-awareness as a prelude to acceptance of his COPD. Chris explained his definition of self-management:

'How to apply yourself mentally to your sickness, to make sure you are aware of what you have got and make sure you are aware of what your abilities are. That is the main thing...Once you've done that then you work on the other things [such as health-related behaviours]'.

Although other authors have referred to awareness in a context of responding to the impact of a chronic condition on a sense of self (Kralik et al. 2004), they have not elaborated further. In addition, self-awareness and acceptance do not appear to have been identified as self-management activities in the current literature.

Self-reliance

Self-reliance emerged as a fundamental concept of the meaning ascribed to self-management by the majority of these participants. There is scant reference to this in the literature. Lesley (I) put this simply when she said, 'I suppose it's [self-management] you've got to try and look after yourself, don't you?' As participants described undertaking activities of self-management relevant to them in managing life with COPD, they noted that self-reliance did not mean that they had to independently accomplish all of the acknowledged self-management activities, but that they had to orchestrate the plan to do so. Participants referred to undertaking responsibilities or tasks, in a context of self-reliance. As Dan (I) said:

'I suppose it [self-management] means that I actually have to organise that part of my life that the medical profession can't run for me, which involves things like exercise and what have you'.

Self-reliance may include a concept of self-efficacy in that as social cognitive theory (Bandura 1986) would suggest, if participants are to be sufficient unto themselves, they would require a belief in their ability to do so. Thus self-efficacy would be seen as a mediator of achieving self-reliance. Self-reliance was seen as doing *for* oneself, not necessarily *by* oneself. Sally (C) told me:

‘Self-management is basically what it says: you manage your own condition, with help from healthcare professionals but you manage it yourself. If you want to live, you do it. It is up to you. If you want to die you can lay [sic] in bed and die’.

For most of these participants the CDSMP was instrumental in creating an awareness of self-reliance. However, not all formed this definition after attending the CDSMP. Sally had attended cardiopulmonary rehabilitation five years previously, and she attributed her recognition of self-reliance as stemming from that programme. She also indicated that her self-reliance was developed by other ‘disruptions’ in her life, as she told me, ‘it is what I have had to learn over the years, sink or swim’. Adjusting to other stressful events in her life equipped her to manage the ongoing changes resulting from life with COPD.

Similarly, Donald (I) who had withdrawn from the programme after the first session alluded to self-reliance in his definition. He defined self-management as ‘Taking control of your life’. This comment points to elements of personal control that will be discussed later in this chapter.

In summary, the meaning of ‘self-management’ to these people with COPD was one of self-reliance first and foremost, coupled with a need for self-awareness in order to accept limitations imposed by COPD and to adopt health-related behaviours in a self-tailoring context while maintaining a sense of independence in one’s life.

The self-developed strategies highlighted in the previous category and the meaning of self-management presented in this category augmented the experience of the CDSMP with or without supervised exercise which is described in the following category, *‘A Shared Experience’*.

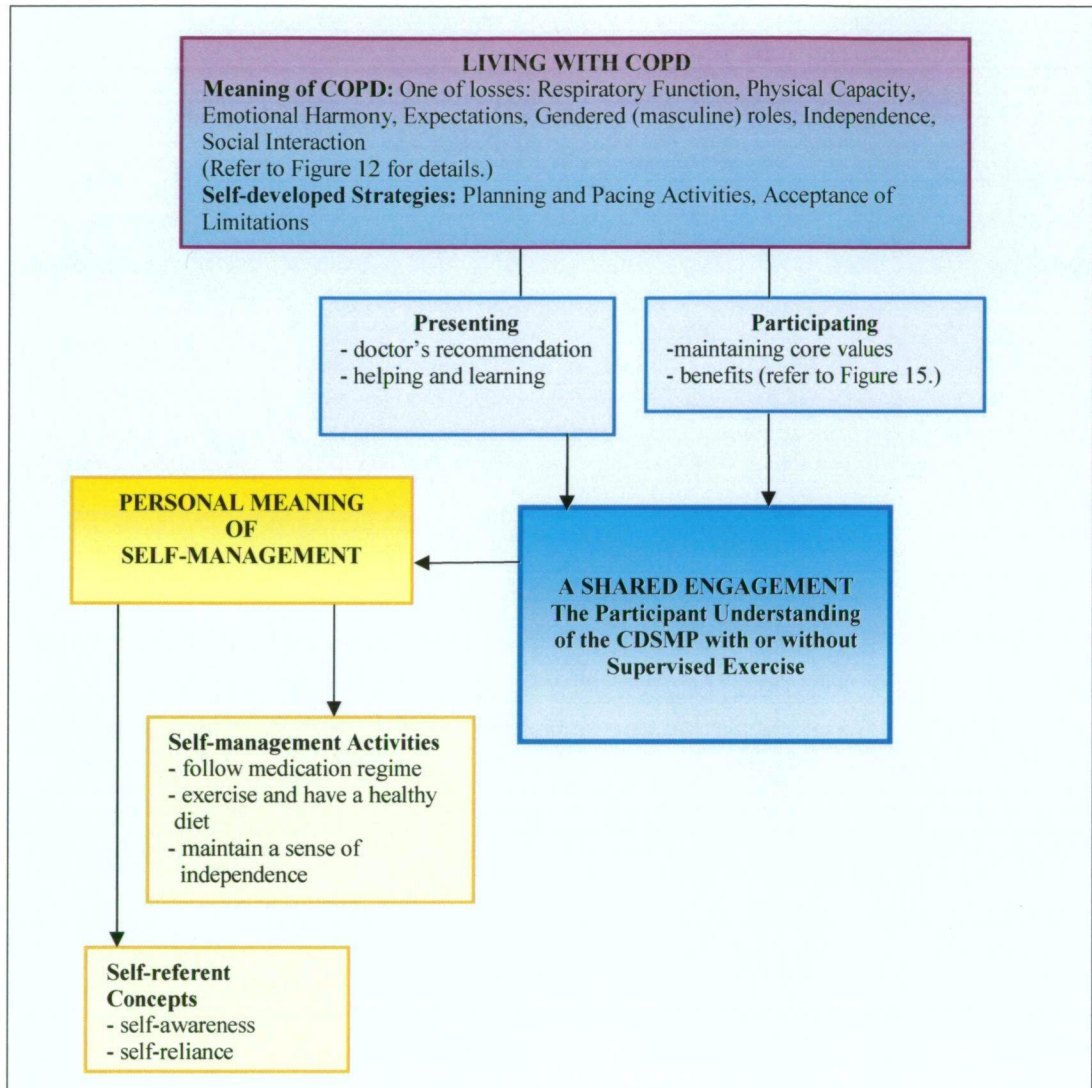
6.2.3 A ‘Shared’ Engagement

Although not every participant took part in the supervised exercise intervention, in describing their involvement with the CDSMP or supervised exercise, participants’ comments suggested to me that they shared in similar motivational influences and benefits arising from both. There were common reasons for presenting at the programme or exercise (a doctor’s recommendation, helping oneself and others and learning) and continuing to participate even when the programme did not meet expectations (maintaining core values). Together these reasons formed the first theme, *‘Presenting and Participating’* of this category.

'The Power of More Than One: Social Benefits', that is relief from social isolation, peer influences and social comparison emerged as benefits and powerful motivational effects operating during the interactions, constituting the second theme. The CDSMP and exercise experiences fostered a focus on areas of importance and achievement for individuals, forming the third theme, *'A Self-Focus'*. In identifying benefits of the interactions, a fourth theme, *'Facilitating Engagement'* was suggested, also showing commonalities between the CDSMP and supervised exercise. These themes contributed to the 'shared' experience of the CDSMP and supervised exercise and will be discussed under this category.

6.2.3.1 Presenting and Participating

The most cited reasons participants gave for enrolling in the study were responding to their doctor's recommendation, altruism and wanting to learn — be it how to help themselves or about their condition. As these findings will suggest, when the CDSMP did not meet expectations, people continued to honour their commitment, to themselves and others, indicating the importance of their values and presentation of self to others as sources of motivation for continuing attendance at the programme or exercise sessions. Figure 14 below depicts these motivational influences diagrammatically. As it will be revealed in the following category, the social benefits of group participation also became a motivation to continue participation in the programmes.

Figure 14: Presenting and Participating*Doctor's Recommendation*

The following vignette illustrates the motivating force of a doctor's recommendation, as well as the need for some people to be externally motivated.

Nigel (I) sat to one side of the desk. He had lived with a chronic respiratory disease for many years, requiring prolonged interactions with medical professionals. He decided he would combine a trip into the city with an interview with me. As such, he elected to come to the hospital to be interviewed. Sun filtered through the blinds as he explained to me why he decided to attend the CDSMP. In doing so, he cast light upon his motivation to adopt or maintain health-related behaviours.

Helen: Why did you come along to the programme?'

Nigel: 'That's a good question. Dr. X thought it would be a good idea...He picked it up that I probably needed something, and also he knows that I am not, that I would like to get more physically better. He knows I'm not too good at that. Actually I'm hopeless'.

Nigel's comments suggest to me that he also acknowledged the need for accepting assistance. However, by framing this as a 'doctor's recommendation', he appeared to avoid any threat to his independence that asking for help may have inferred. Other participants voiced similar sentiments as they told me that they came because 'Dr. X recommended that I come' (Max [C]) or they needed a 'refresher course' (Sally [C]) and 'that I come back [to the programme]' (Mark [I]). These data indicate that a doctor-recommendation is something that could be encouraged for future programme recruitment and as a means of maintaining a sense of independence, when the act of accepting help is interpreted as deciding to follow the recommendations of a doctor. Whether or not a recommendation from other health professionals would have been as influential has not emerged from these data.

Helping and Learning

Some participants gave altruistic reasons, coupled with a desire to learn or to help themselves, as their motivation for commencing the programme. Barry (C) wanted to help me with my research, as well as helping himself. His comments also reinforce the influence the doctor's voice referred to previously, as he told me:

'Dr X, he said about it, that you were having another class that perhaps I could help you (with) as you were doing a paper on it, and help myself at the same time'.

Gary (I) also wanted to learn and to help others in a similar situation. He noted:

'It was a matter of information, a matter of sharing something, of learning, and if I was doing something that was eventually going to help something else, well, why not'.

Alice (C) also commenced to help 'the lady who was doing a PhD and needed the information because she was doing a study', adding, 'It wasn't really for my benefit it was for your benefit'.

Ben (I) was 'always interested in learning more. I am living with emphysema and I have to learn as much as I can about it so I can accept it...'. Similarly, increased knowledge was sought by Larry (I) to aid the ongoing adjustments he was being forced to make as his COPD progressed.

While Larry, Ben and others found the information they were seeking from the programme, this was not the case for Gary (C) who had hoped for more education and Ewan (I) who found the content a 'bit repetitive'. Similarly, Nancy (C) had also

hoped for more specific education. She was initially thrilled to be enrolled because she wanted to

‘get some insight to help myself...I wanted to learn about emphysema [COPD], how the lungs work, and how the oxygen works, and how I can do things to make myself feel as good as I can for as long as I can.’

However, when I asked, ‘How did the programme go about meeting those needs?’ she replied, ‘It didn’t’. She did not gain the knowledge she appeared to be seeking and she was too embarrassed to speak out in front of the group because of her perceived lack of knowledge. However, Nancy continued to attend, reflecting her core values of commitment, a finding I will present in the following theme, *Commitment: a Source of Internal Motivation*.

Similarly, Larry (I) would have preferred to have instruction and practice with his inhaled medications and more advice on formulating a symptom-related action plan. As he said, ‘There is nothing like someone standing up there and showing you what to do’. Correct use of medications and responding to symptoms are recognised as important tasks in both the self-management literature and the COPD-X guidelines (Battersby et al. 2003; Clark et al. 1991; McKenzie, Frith & Burdon 2003).

I was concerned to hear these comments relating to unmet expectations. While I recognise that no intervention can meet the needs of all, these comments serve as a reminder that as health professionals we need to be continually mindful of what our patients are seeking, ask if those needs are being met and strive to meet those needs. For some participants, these data indicate that the CDSMP with its companion book did not provide enough condition-specific information.

I went on to ask these participants why they continued to attend supervised exercise or the programme, especially if it did not meet their expectations. The motivational influences for continuing their participation are presented in the following sub-themes.

Commitment: a Source of Internal Motivation

Whether or not expectations were met, what emerged as the principal motivation for continued participation was a core value of responsibility, of honouring commitments. Core values are referred to in the literature those to which people refer

when evaluating themselves and that are retained as people manage the impact of a chronic condition on their self-perception (Yoshida 1993). Overwhelmingly, all the participants who continued to attend the CDSMP saw themselves as people who honoured commitments and who were reliable, and this appeared to be a powerful source of internal motivation.

What these data suggest is that the core values of honour and reliability appeared to be fundamental to the self-presentation of these participants, serving to enhance self-esteem in the face of severe disease and restrictions. As I have described, Nancy (C) found the programme did not meet her needs, yet she attended all sessions, because she 'felt it was my duty to, because I had signed up to come for the six weeks'.

Others affirmed Nancy's sentiment:

'I think you have to follow things through...It is no point in starting if you are not going to finish. I have always been like this'. (Carol [C])

'I am not one to leave half way through it, and I didn't think it was fair on you and your staff to miss any episodes, as you put a lot of effort into it. So the least we could do was to be regular attenders'. (Barry [C])

And from Alice (C):

'I like to fulfil a commitment. Once I say I will do something, I will try like hell to do it'.

Colleagues have suggested to me that these comments reflect the values common to those of this age group, which averaged 66.6 years. However, it is not my intent to study the ethical code of older individuals, nor to comment upon differences, if any, between them and younger people. These core values were held independently of the CDSMP. However, the CDSMP experience served to strengthen these values in that it seemed important to them that I, as a leader and the researcher, saw them in a positive light even when the programme fell short of their expectations. In this way their self-presentational behaviour maintained a positive reflection of themselves in my eyes and in their own (Brown 1998b) .

The responses might be viewed as socially desirable, in that participants gave an answer they thought I wanted to hear. To me, this was not so. If this were the case, it might be expected that they would have all endorsed the CDSMP, not offering any

criticism, particularly as they knew the CDSMP was part of my research. Instead, a sense of commitment to self and others prevailed.

Commitment also constituted a source of external motivation, especially for ongoing participation at the exercise sessions, as presented below.

Commitment: A Source of External Motivation

The motivating influence of commitment to others was suggested by the comments of some who attended the supervised exercise sessions. Dan, Gary, Nigel and Mark attended supervised exercise (I). They readily admitted that they needed the motivation from making a commitment to others to attend exercise sessions. Mark described himself as 'not a stickler for exercise'. An added value of supervised exercise for them was in assisting them to evaluate what they did on a daily basis, integrating exercise into daily activities and achieving exercise recommendations. In this way they avoided suggestion of a 'regimented practice' (Dan) and the commitment to attend helped to maintain motivation to exercise. Gary agreed:

'Coming to the gym is a form of exercise. So I intend to keep coming to the gym and doing that, and it does hurt, but it [commitment] is one way to get me to do more exercise than I do'.

Chris (C) had also noted that he needed the external motivation of committing to others to keep exercising. He said:

'Well, I think I need an appointment to be somewhere, and I know when I get there that I have to do something, because I am obligated because I have committed myself, and that is what you have to do, if I never said to you that I would do something, invariably I wouldn't do it. I am just lazy'.

It was with some alarm to me that his comments suggested self-blame and lowered self-esteem for not doing what he thought he 'should' do. That is, he did not ask if he could attend an exercise group when the CDSMP without exercise failed to meet his expectations. I reiterated to Chris that he would have been able to attend supervised exercise following the CDSMP. Nevertheless, he blamed himself for not pursuing this further.

These experiences raised the ethical question for me as to the global 'safety' of intervention programmes designed to facilitate behaviour change. I recognise that the CDSMP could not be expected to suit all people. However, of those who attend, if

negative self-esteem is reinforced for some people, there is a risk of increasing the likelihood of depression, a recognised comorbidity for people with COPD (Yohannes, Baldwin & Connolly 2000). As leaders, we need to be aware of this potential adverse outcome.

6.2.3.3 The Power of More than One: Social Benefits

As these data will highlight, there were group processes that became benefits, forming a unifying thread across the interviews and between the CDSMP and supervised exercise. A benefit and also a reason to commence the programme or exercise sessions was relief from social isolation. Other major processes and benefits involved learning from similar others, being influenced by the achievements of role models (Bandura 1997), and engaging in social comparison (Buunk et al. 1990; Festinger 1954). I have explained these processes in the literature review. Being with similar others provided empathy and credence to their own experiences. These experiences are described below.

Relief from Social Isolation

Social contact and relief from isolation was the reason some participants enrolled in the study. Mary (I) observed that she would get ‘out of the unit and...meet people at the same time’. As this benefit of social interaction was reinforced, it became a reason for continued attendance at the programme and supervised exercise. Sally (C) explained the benefit of interacting with others. She said:

‘I would say you need it because you can feel isolated in your disease...[yet] you want to be isolated [from infections] and be precious about yourself a bit. It is really good with the round table sessions [of the CDSMP] and we get to talk a bit, and we all have that in common, and with the last supervised exercise [Sally had attended a cardiopulmonary rehabilitation programme previously], we were all exercising at once so we still had that social interaction. You could be riding the bike and talking to the one next to you, or on the trampoline walking thing, if you still had the breath you could talk to the one next to you...when you are doing it at home you have no-one to talk to’.

Her sentiments were echoed by others. Ben (I) commented he found ‘it much better to do it in a [supervised] thing where there are other people doing [exercise] than if I just have to get up and do it at home’. Len (I) enjoyed the ‘social aspect to it’. Nancy (C) wanted ‘companionship’. Carol (C) noted that ‘living on your own, you just become a bit stagnant’ and group participation ‘pushed [her] along’. Gary (I) lived alone and found the social contact of the exercise group valuable. He commented:

‘There is more to supervised exercise than exercise itself. It is social as well, which to some people probably doesn’t matter, but there are a lot of people that it does’.

Gary’s opinion synthesises the findings in the following theme wherein the data suggests that the social processes, especially the influence of peers, operating within the supervised exercise sessions were of major importance to participants. The processes were perceived as a benefit of the CDSMP with or without supervised exercise and, in themselves, appeared to me to become a reason to continue attendance

Peers: A Source of Motivation and Learning

Learning from and comparing with role models served as a motivation for behaviour change, particularly for commencing exercise. Carol (C) had not been randomised to supervised exercise, yet she attributed the influence of role models and downward social comparison (which I shall discuss later) during the CDSMP as helping her to begin exercising. She said:

‘It is just the fact that there were people around me who were going through a similar thing and they threw ideas in and it was so good...I think it comes back to the fact I could see other people doing things and I thought they were probably in a worse condition than me and they were getting out and walking and doing everything, for instance X, she could only walk for five minutes, and I thought, I have to do this’.

Similarly, the motivation from role models was evident in the supervised exercise group. Mary (I) explained:

‘I honestly believe that gym is the answer for people like me. You spur each other on. You don’t retreat into your shell. You see someone on a bike and you go and get on one too’.

Hoping to learn from others with COPD served as initial motivation for commencing the programme. This then became a positive outcome of the experience, as noted by Len (I) who explained he learnt from others and ‘gained a bit of confidence.’

Structured learning from and sharing with role models were seen as the differentiating features of the CDSMP when compared with more traditional multidisciplinary approaches to rehabilitation. Participants who had attended traditional approaches previously remembered little of the educational component where there was ‘a person standing up giving you a little talk’ (Carol [C]), which according to Larry (I) caused ‘...you [to] lose the path a bit’. In contrast, all

remembered information relevant to them when they learnt it in an environment that encouraged learning from people who ‘know what I know...we all felt the same...we have all got a problem and everybody seemed to relate’ (Ben [I]). Sally (C) endorsed the CDSMP ‘because it is really good, sitting around talking and finding out little tips from people [like me]’.

Peers: A Source of Identification

For the majority of participants, being with people who had COPD appeared to be a strength in the way we offered the CDSMP at our hospital, that is, presenting the generic model to a condition-specific group of people. Knowing that others understood the impact of breathlessness emerged as the single most important factor in identification, affirming their experiences and a positive self-perception. As Barry (C) observed, those who do not have a breathing problem ‘find it hard to believe that you can’t do that [breathe]’. Max (C) was enthusiastic as he told me how he gained support from others and that ‘by talking to those people, you know you are not going mad, you know it is part of the complaint’. Lesley (I) suggested that by realising her symptoms were shared by others and ‘it’s not just you’ was helpful in moving forwards in managing her condition.

Mary (I) found that by identifying with others she reaffirmed a positive self-perception, discarding a view of self to which she did not ascribe. A re-evaluation of the self has been described by Charmaz and others in relation to living with a chronic condition (Charmaz 1987; Yoshida 1993). However, Mary’s re-evaluation appears to be more in response to identifying with others perceived as similar to herself, rather than to the impact of her chronic condition per se, as has been suggested by the aforementioned authors. She explained:

‘I think it was just mixing with people, making my own decisions, being part of the group, all of those things just made me realise I wasn’t this person who did for others. I was there. Just being part of a normal lifestyle made me realise that I was still there, that I hadn’t gone away’.

There were some participants who did not identify with some of their peers, although this was not a negative enough experience to result in withdrawal from the CDSMP.

Max (C) persevered, despite a personal difference, stating how he ‘nearly spat the dummy. Then I’d calm down and think, “I have to go back. I am getting somewhere.

I am meeting these people in real life and don't let that person upset me'''. Over-familiarity led to some negative interactions, suggesting that identification is not always mutual. Such situations require tact and understanding, and are seldom reported in the literature. They indicate the importance of leaders being aware of possible adverse interactions within the groups, and to be able to address these promptly.

Some participants also identified with the leaders. Carol (C) and Lesley (I) saw me as a peer, with whom they could identify, noting that I have asthma 'which helps I think, because you are in that situation the same as us' (Lesley). Additionally, participants saw value in having leaders who 'work in the field...understand that field...[and] are experienced' (Ben [I]), and from Alice (C):

'I was much happier to have someone that I considered to have more experience, rather than another patient'.

As well as identifying with similar others, participants engaged in a second process — social comparison — whereby they actively compared themselves with others in either an upward (comparing with those perceived to be better) or downward direction (comparing with those perceived to be worse) (Buunk et al. 1990). As suggested by the following data, most participants engaged in downward social comparison.

Social Comparison

Downward social comparison (Buunk et al. 1990) served as a bolster to self-esteem. Lesley (I) noted that 'people are worse off than you as well, so you think how lucky you are'. Chris (C) added:

'I don't know, well, I thought I was sick, until I seen [sic], them and that was what really opened up my eyes...well it lifted me...I was only short of breath when I walked. He (Ray) was short of breath when he was talking, and that really opened my eyes that I wasn't as bad as I thought I was...That poor old girl that [sic] was in the chair with the oxygen cylinder, she was bad. I thought I wasn't as bad as them'.

For Max (C), social comparison would have been useful had he been randomised to the supervised exercise intervention, 'to see how much others do, to compare...'.

There was one participant interviewed for whom downward social comparison was a negative experience. Donald (I) withdrew from the programme. Without being asked, he volunteered his reasons:

‘I didn’t want to be surrounded by the cretins that were there...I thought that they, they all had a lot of problems with overweight. They had a very big problem with regard to their breathing...I couldn’t be bothered wasting my time in there with that mob...I thought it might have been looking at programmes to help me. I felt we were looking at programmes to help the lowest common denominator, and I wasn’t that’.

One other participant withdrew from the programme for similar reasons. However, she declined to be interviewed. Leaders need to be alert to negative interactions and offer alternative arrangements. I invited Donald and four other participants who withdrew early from the programme to see me to discuss how else we could meet their needs. Donald was the only participant who availed himself of this, and chose an individual appointment with telephone follow-up.

For participants who continued to attend the programme, social processes of learning from and being influenced by peers is an acknowledged source of self-efficacy information (Bandura 1977, 1997) and, as the data revealed, these sources were influential in the CDSMP and supervised exercise. A consideration of the self evolved, largely as a result of setting action plans. Goal attainment developed mastery for that behaviour (often exercise), and attendance at supervised exercise enabled reinterpretation of symptoms or stressors. Both these influences are proposed as sources of self-efficacy information (Bandura 1986). These processes are apparent in the following theme.

6.2.3.4 A Self- Focus

As the following findings suggest, setting action plans heralded self-consideration, which I will explain in the following sub-theme. During the CDSMP, participants set weekly behaviour-specific action plans of their choice, being guided by the leaders who followed a chart and the structured manual (LorigHolman et al. 1999). As I was one of the leaders for the entire study, I was able to ensure as much as possible that the participants’ understanding of action plans paralleled my own.

Although the CDSMP does not include supervised exercise, it is not surprising that participant action plans frequently included exercise because it was the intervention.

Completing action plans for exercise and attendance at supervised exercise appeared to me to facilitate exercise self-efficacy, informed predominantly by enacted mastery. Reappraisal of potential stressors or barriers was more evident during supervised exercise (Bandura 1998). The data suggests that learning action planning with resultant goal achievement enhanced perceived personal control (Petersen & Stunkard 1989).

Self-consideration

One of the tenets of the CDSMP is to plan around something the participant *wants* to do, rather than something they or someone else thinks they should do (LorigHolman et al. 1999) This process of focusing on what *they valued* led people to consider themselves first, although not in a selfish sense. I have termed this process ‘self-consideration’. Carol (C) had seen herself as self-sacrificing. As she began to set plans for what she wanted to do and to reflect upon herself, she noticed a shift in her self-concept:

‘I have learned through the programme as well, that you have to think of yourself a bit more, which I have never done. I always put myself last... You just have to say to people, “I’m sorry. I just can’t do it today”....I think I have more strength or assertiveness’.

Alice (C) also explained the importance of setting goals for *oneself*, of considering oneself, suggesting a shift towards internal motivation. She said:

‘I think it was the kind of thing that would help to keep a lot of us motivated and I think I made a commitment to walk 30 minutes a day and back as often as I possibly could, mainly because I had made the commitment to the programme rather than me. Now I have to make a commitment to me’.

The step from extrinsic to intrinsic motivation is an important one. People who are internally motivated are likely to maintain interest in an activity more than those who perform with the expectation of reward from others (Brown 1998a). For exercise, intrinsic motivation would appear to be an important factor in maintaining the behaviour once supervised programmes are finished.

Peter (C) had previously indicated he was ‘pretty narky’ about not being randomised to supervised exercise sessions because he perceived he needed this. However, the data suggest that, like Carol (C), as he set action plans addressing his preferences, he developed self-consideration that fostered intrinsic motivation for walking. His

walking increased, and he engaged in a cycle of self-regulation, assessing his achievements and progressing accordingly. This points to a corresponding increase in his self-efficacy for walking so that attendance at a supervised exercise session was no longer deemed to be necessary by him. He explained:

‘...the other thing that the programme did was that it forced me to focus a bit more on myself, in that I enjoyed going for the walk [his action plan]...At first I thought it was going to be a chore, but then I enjoyed doing it and so I started to do things which were obviously important to me, that I wouldn’t have rated as important to me before the programme...and it streamed through from that point. The programme was doing something for me...I started to do things for me which I hadn’t done for a long time...I can do things I didn’t think I could do...it has made me think I still have a [future], it has made me optimistic about my long term prospect...’.

Similarly, Simon (C) who did not attend supervised exercise, stated:

‘It [the CDSMP] has helped me to achieve a higher level of exercise than I would otherwise have done, it has helped me to organise my directional thinking and discipline if you like, to set goals and progressive goals at a reasonable level that I think I can attain, not only in the exercise related activities but other activities’.

Larry (I) also indicated the importance of learning that goals can be achieved. He said:

‘Pleased I did it [supervised exercise]. Even for the effect I knew I could do it, it gave me confidence to know that I could do it’.

Such an increase in confidence suggests an increase in self-efficacy for exercise (Bandura 1997). Peter’s (C) and Simon’s (C) comments illustrate Bandura’s observation that as robust self-efficacy for a particular behaviour develops, it has the potential to generalise to other behaviours (Bandura 1986). In doing this, a sense of personal control over one’s life develops (Petersen & Stunkard 1989). While it is encouraging that perceived personal control appeared to be enhanced following the CDSMP, the question raised for me now is, how is this shift in perception maintained? These data indicate the short-term benefits: but how is action planning behaviour sustained in the longer term? These data cannot address these questions.

These participants’ experiences suggest a shift towards internal motivation and increased personal control as people realised ‘self-consideration’ in setting action plans and developed mastery, especially for exercise, as their plans were completed. As exercise mastery appeared to be facilitated regardless of whether supervised

exercise was attended or not, I sought to understand if participants identified other influences during the exercise sessions. The following data suggest they did.

Self-Regulation During Supervised Exercise

As well as the data suggesting skills mastery, participants' comments suggest facilitation of exercise self-efficacy during the supervised exercise sessions by the self-regulation that occurred, particularly through reappraisal of stressful information. Peter (C) noted that the CDSMP content did not indicate which exercises would be necessary for people with COPD, and although the CDSMP has a companion book, it may not be sufficient for all people. Nancy (C) elected to attend supervised exercise after the CDSMP. She observed 'you have to have the knowledge first', adding that once she witnessed her ability to undertake exercise (suggesting skills mastery) and knew she was safe (reappraisal of stressful information), she was 'enthusiastic to keep doing this, not just now and again, but to keep [going]. It fired me up'. Carol (C) agreed:

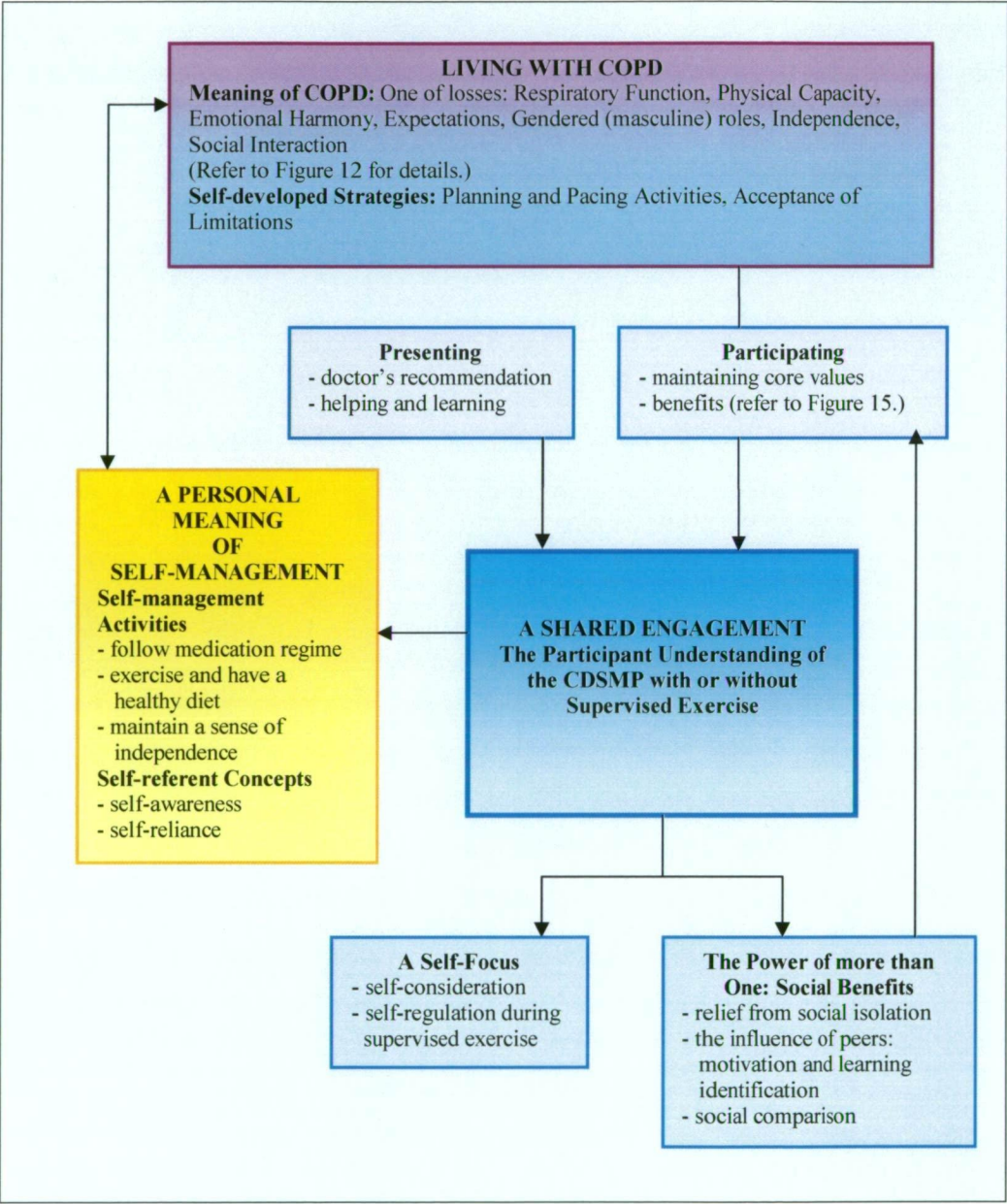
'Initially I would rather be supervised until I was sure I was doing things the right way, because there is a right and wrong way. If you are doing it incorrectly, you are in more trouble really. So I would rather come and have initial supervision'.

Sally (C) suggested that supervised exercise sessions might serve as a source of fear reduction and reappraisal of stressors for those who like her might be 'frightened of exercise and just need that little bit of a push' and help people to learn through self-regulation that 'you can exercise without keeling over and dying'. Dan (I) found the monitoring and interpretation of physiological parameters such as heart rate, oxygen saturation and blood pressure to be beneficial in building a sense of safety and increasing confidence 'in how much activity you can achieve'. This increase in confidence suggests facilitation of self-efficacy for exercise by learning to manage potentially stressful sources of information (Bandura 1986, 1997).

The foregoing findings reveal a unifying thread of motivational influence to present and then continue participating in the CDSMP with or without supervised exercise. The benefits of group participation in particular linked the CDSMP and supervised exercise sessions, both as a benefit of participating and as motivation to continue. Self-consideration evolved as people began to consider their goals. Setting action plans, in particular during the CDSMP, facilitated a self-focus. As action plans were completed, self-efficacy and perceived personal control appeared to be augmented.

Supervised exercise provided additional self-efficacy information as people engaged in self-regulation of exercise, promoting skills mastery and reappraisal of stressors. Figure 15 below shows this interaction.

Figure 15: Social Benefits and a Self-Focus



At this point in my analysis I stepped back from the data and asked why the CDSMP and the supervised exercise sessions we offer share commonalities, when the former is a very structured intervention wherein a manual is provided and programme fidelity mandated, and the latter is less structured with no universal approach but a focus on undertaking individually-tailored exercise. These data point to a participant-

centred framework meeting participant-identified needs and preferences. This suggests to me a need for health professionals to consider how interventions meet the needs of participants and ‘fit’ programmes with their preferences. As previously mentioned, this will be explored in the *Discussion of Findings*. As a prelude to the discussion, I will present findings illuminating participant recommendations reflected in the theme, *Facilitating Engagement*, below.

6.2.3.5 Facilitating Engagement

Participant comments following attendance at the CDSMP or supervised exercise point to shared participant-identified needs and preferences. Four participants had attended traditional rehabilitation programmes previously and, in commenting upon the CDSMP and the current supervised exercise sessions, they drew comparisons between their earlier experiences and that of the CDSMP. While this is limited data, I present it as an indication of a need to pursue further research in this field. These data highlight a need for health professionals to listen to the voices of participants and take into account what is important to them when engaging in interactions.

The experience of the CDSMP or supervised exercise influenced their preferences for future interventions, as the following sub-themes reveal. They referred to a preference for guidance with shared decision-making, rather than following directions. They suggested choices be offered to address issues relevant to them and that their preferences be respected. These elements linked the CDSMP and supervised exercise experiences. Figure 16 below diagrammatically depicts the relationship.

Facilitating Engagement with the CDSMP

Four participants who had attended a traditional programme previously, as well as the CDSMP, drew comparisons between their experiences. These data support the focus of addressing participant-identified problems and preferences during the CDSMP, as described earlier in *Chapter Two*. The value of participants addressing problems relevant to them, rather than a multidisciplinary team giving information they thought was needed, was suggested by Larry (I) and Ben (I). Larry referred to his experiences at a traditional multidisciplinary programme attended two years previously, noting he did not ‘remember getting a terrible lot from a lot of people [multidisciplinary team members] coming and talking about certain things

[discipline-specific topics]'. For him, the CDSMP sessions '...where the people with the actual problems [participants] spoke were much better, bringing it down to bedrock [that which is relevant to the group]'. Larry claimed that listening to health professionals using a didactic delivery style was not as successful, because 'I don't think it jolted a person to make it sink in'. Ben also noted that with the number of different health professionals giving lectures in the traditional approach, 'there didn't seem to be any continuity' and this was counterproductive to learning for him.

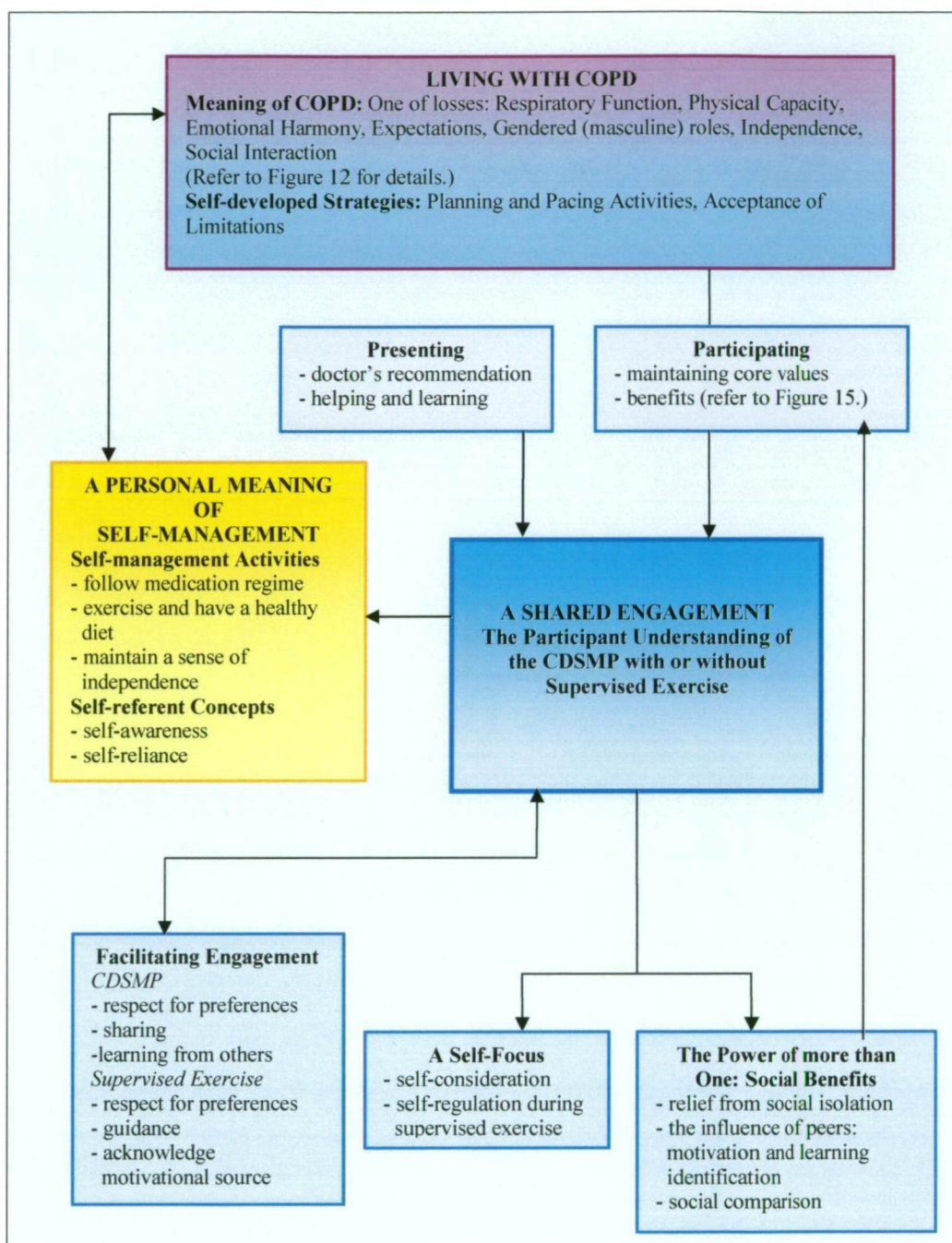
The CDSMP process with its group sharing and learning through interactive brainstorming activities and guided feedback sessions, rather than a didactic lecture format, is a differentiating feature between it and more traditional approaches. It was deemed a positive experience. Ben continued:

'It [traditional rehabilitation] was more or less that you are here and we are going to tell you about it. That was one of the big things. It was like teacher/student, "You have this wrong with you and this is what you have to do and this is how you have to do it. That's it. Now go away and do it". Whereas here [CDSMP], you ask questions... This [CDSMP] is what you *want* to do, the other you've *got* to do'. [Ben's emphasis]

Ben's comments are reflective of self-consideration, which I presented earlier in this category. They also relate to respect for his preferences. In agreement with Ben, the majority of these participants found the CDSMP to be a positive experience.

However, as was revealed earlier in the findings, the CDSMP did not meet the expectations of all the participants interviewed. Three participants expressed areas where the programme failed to meet their perceived needs, with at least one person withdrawing. I indicated earlier that we must ascertain the barriers to attendance and offer alternatives.

Figure 16: Facilitating Engagement



Facilitating Engagement with Supervised Exercise

For the past 12 years I have worked with individuals to establish their exercise goals and programme. Individuals are guided and offered a choice as to the type of activities and the order in which they will be performed, taking into account recommended exercises for people with COPD (Australian Lung Foundation and Australian Physiotherapy Association 2006). While people attend together as a group, exercise programmes are tailored to individual ability and preferences, with

each person following their programme, rather than being directed to a circuit or performing a set of mandated group exercises.

Ben's observations lend support to the individualised focus of our exercise sessions wherein we offer a menu of activities. He identified the elements in our programme that he found favourable, as he drew comparisons between it and a rehabilitation exercise programme attended previously at another hospital. He said:

'It [our programme] was supervised in that the Physio, either yourself [sic] or someone else, said, "This is the way it's best to be done". It was supervised and guided how to do it right and how to do your warm up exercises and how to do them right. So that was supervised and then it was, "We suggest ten minutes on the bike", but you never said, "Ten minutes at 20kph", so while there was guidance there it wasn't forced... You could more or less find your own level and work at the pace that suited you. It wasn't with someone standing over saying, "More, more, more!" and that's what I found with the [other] one was "More, more, more! You're not doing enough"... I just felt, well nobody's asking me how *I* feel or what *I want*'. [Ben's emphasis]

Ben's comments point to partnership, guidance, informed decision-making and respect for individual preferences. His recommendations for future programmes and supervised exercise add to this. He said:

'I think it should be suggested... "This is what the programme is. We are going to have a meeting here once a week [CDSMP], and on another day there is going to be an hour [of supervised exercise], and we suggest that everybody comes to it and at least come along and see what you think". Then when they come along, say, "This is what we do. This is how we do it", and then let them, with a little bit of encouragement, let them evaluate whether it's [of supervised exercise] for them or not, because I thought it was a good idea'.

Larry (I) also indicated that the individual's preferences and motivation should be taken into account as he noted that 'those that do the exercises will do them but some of the others need pushing'. Barry (C) added:

'No, it [supervised exercise] wouldn't do me any good. But there are others that like that [supervised exercise]. So rather than conscript them to exercise or not, let them make the choice'.

Barry's observation was supported by others who wanted to choose supervised exercise, recognising a need for external motivation. Mark (I) explained his reasons for continued attendance at exercise sessions:

'Because I feel it is helping me, and as I said earlier, I am not a great one to take the time to do exercises on my own'.

For Chris (C) the choice of supervised exercise would provide the opportunity to 'compete' against others 'because I am always used to playing competitive sport'. When asked about competing against himself, his reply was, 'That's where I fall down. I don't'.

Data presented earlier suggests that those who would benefit from supervised exercise are individuals who prefer to learn in a 'safe' environment, who benefit from committing to others, from monitoring physiological parameters, from social comparison and the influence of peers or role models. The above data also indicate there are people who recognise that attendance at a group provides a source of external motivation. These are preferences which should be acknowledged.

Offering a choice and then respecting participant preferences emerged as the key recommendation for supervised exercise and for the CDSMP. All of the participants interviewed suggested that supervised exercise should be offered, with just under half of the group noting the importance of a choice. Len (I) thought that 'it should be up to the individuals what suits them. You are going to find all different sorts of individual feelings about it'. Others indicated that participants should be able to choose which component(s) they wished to attend. As Mary (I) said:

'I think an exercise programme by itself would work just as well as an exercise programme with a self-management programme. I think probably the ideal answer is some people need one and some need the other'.

Participants' experiences showed shared motivational influences for adopting or maintaining health behaviours operating in the CDSMP and the supervised exercise sessions. These data suggest that linking these two seemingly different interactions is an overarching participant-centred framework, which I will explore in the following chapter.

6.3 Chapter Summary

In summary, these findings cast light on life with COPD and how these participants have responded to their changed circumstances. Participant attitudes and attributes influenced their interaction with the CDSMP with or without supervised exercise. This interaction in turn influenced their behaviours, pointing to the influence of shared social-cognitive processes as additional skills were learnt for managing life

with COPD. These data suggest the importance of meeting participant-identified needs and preferences and point to a participant-centred framework. I will discuss these findings in *Chapter Seven, Discussion of Findings and Conclusions* and draw implications for clinical practice in the conclusions following the discussion

7

CHAPTER SEVEN:

DISCUSSION OF QUALITATIVE FINDINGS

7.1 Introduction

This qualitative arm of my research emphasises the importance of listening to the voices of individuals with COPD. Statistics and physiological measures help to chart the rise and nature of the condition, providing objective evidence-based information on which to base policies and interventions to better manage from a population health and biomedical viewpoint. This is important because without such evidence the best possible healthcare and management of disease may be compromised. However, it is the lived experience of the participants that enriches our understanding of the self-management undertaken by people with chronic disease such as COPD, and of the interactions these people have with their healthcare providers during interventions such as the CDSMP or supervised exercise.

The findings highlight the losses experienced and the practical and emotional impact of COPD on everyday life. These descriptions contextualised the self-management actions participants take to handle the often fluctuating impact of COPD on their day-to-day lives.

The CDSMP and supervised exercise session experiences suggested common motivational sources influencing behaviour, situated in a framework that facilitated engagement. This appeared to be more important than the content of the CDSMP or exercise per se. This participant-centred framework will be discussed later in this chapter.

The value of setting action plans in facilitating self-efficacy for the behaviour was indicated by these data. I have also taken note of comments suggesting a negative

interaction with the CDSMP, or where it failed to meet expectations. Such observations are not often reported in the CDSMP literature. I view these comments as 'signals' to those who lead the programmes. In this way, the voices of these participants will inform clinical practice within our hospital.

7.2 *Living with COPD*

As previously described, life with COPD is one of breathlessness, resulting in losses of physical capacity and emotional stability, expectations, roles and independence, all of which restricted social activities. The comments from these participants emphasise the influence of their bodily experience of COPD on the meaning of life with this condition (Kelly & Field 1996). These data support other studies involving participants with COPD in the medical literature that reported limited physical activities, although the authors did not discuss this in its relation to an understanding of COPD (Guthrie, Hill & Muers 2001; Oliver 2001; Seamark, Blake & Seamark 2004).

I also observed physical activity limitation relating to gender and role expectations, supporting recent research, (Hansen, Walters & Wood Baker 2007). This was particularly so for the men who saw undertaking the heavier household tasks as their responsibility and was associated with feelings of inadequacy and frustration as they were forced to relinquish a former view of an active physical self due to breathlessness. The loss of self I observed in these data lends support to the earlier work in this field (Charmaz 1983). As their COPD with its pronounced breathlessness progressed, the difficult emotions suggest a tension between the actual abilities of their bodies, and a preferred self-presentation as being men who could complete the heavier tasks they regarded as 'masculine'. Their bodies did not 'fit' their self-view, resulting in discord evidenced as a raft of difficult emotions. The disruption of their taken-for-granted assumptions concerning roles that could no longer be maintained added to their frustration, supporting the seminal work of Bury with people with arthritis (1982) and indicating that this concept transcends conditions.

The disturbance of roles resulted in some participants needing to seek and accept help. For some, particularly the men, accepting help represented an erosion of

independence, again emphasising the dissonance between a preferred self-presentation and physical capacity. My observation supports the suggestion of others that independence is prized in the Australian culture, and to perceive oneself as dependent causes feelings of marginalisation and stigma (Millen & Walker 2001; Walker et al. 2003). This resulted in discrediting statements of worthlessness, being a burden and self-blame, all of which point to a loss of self (Charmaz 1983), and the stigma of not being like 'normal' others (Walker et al. 2003).

One participant (Max) was able to independently reframe his view of seeking help as equating to dependence and uselessness, to one where seeking and accepting help became a resource to regain his independence and hence his sense of self as a worthwhile person, mitigating his self-imposed stigma. In addition, the data suggest that by recognising his limitations, adjusting the work he did and enlisting help to complete the task, Max appeared to be using both primary control (modification of the task) and secondary control strategies (accepting limitations), which served to enhance his perceived personal control (Chipperfield, Perry & Menec 1999). While I could not draw conclusions from this man's situation alone, his situation suggests a benefit of reframing the meaning of 'dependence' ascribed to seeking help, and explaining it from a different viewpoint, as a resource to be utilised.

Some participants described a life of restricted social interactions. This observation is not new. Others have also described the shrinking social world of people with chronic conditions, noting the impact of physical limitations on these interactions (Kelly & Field 1996; Partridge 2004). These participants spoke of limiting their social activities, not simply because they could not physically undertake what might be required, but because of a desire to avoid actual or perceived unwanted attention, suggesting internalisation of stigma (Walker et al. 2003).

An alternative explanation for voluntary social avoidance might be a strategy to manage the negative impact on self-esteem that such potentially embarrassing and devaluing encounters might engender (Royer 1995). However, I did not glean from the interviews that participants took such actions with a positive outcome (preservation of self-esteem) in mind. Restricting their social activities resulted in further diminution, not preservation, of their self-esteem. The participants' stories of social avoidance further emphasised the pivotal role their bodies have in the

relationship between their social contexts and their self-perception (Kelly & Field 1996).

Participants brought these above experiences and their self-developed self-management strategies with them to the CDSMP and exercise encounters. It is beyond the scope of this study to disentangle the influence of prior experiences with that of the CDSMP or supervised exercise on the strategies and meaning of self-management, unless this was identified by the participant.

7.3 Self-Management: Strategies and Meaning

These data reinforce that living with a long-term health condition is complex. They also point to the self-managing strategies people have developed in the course of life with a chronic condition. The sociological and other literature is rich in studies that have documented this aspect (Bury 1982; Carricaburu & Pierret 1995; Charmaz 1983, 1987; Clark et al. 1991; Corbin & Strauss 1988; Fagerhaugh 1993; Kelly & Field 1996; Kralik et al. 2004; Pound, Gompertz & Ebrahim 1998; Radley & Green 1987; Royer 1995; Scambler & Hopkins 1986; Strauss 1973; Williams 1984; Williams 2000; Yoshida 1993). Recently Bury and colleagues have brought the seminal sociological studies together, emphasising that people with chronic conditions have developed strategies and skills to manage their lives, independently of any structured interventions (Bury & Gabe 2004; Bury, Newbould & Taylor 2005). This is an important consideration, as some literature suggests that people with chronic conditions need to be taught self-management skills (Fu et al. 2003). The data from my study lend support to Bury et al.'s (2005, 2004) conclusions, although I could not infer that the strategies the participants used prior to attending the CDSMP had been developed without any external influence, especially as these participants had many years of interactions with healthcare professionals.

In defining what self-management meant to them, participants described self-tailoring activities by planning and pacing, supporting earlier studies (Fagerhaugh 1993; Kralik et al. 2004). Acceptance of limitations was also identified and has not been reported widely in the literature. These two self-management strategies were referred to by participants when relating experiences prior to attending the CDSMP with or without supervised exercise.

In defining their understanding of self-management, participants drew upon activities they perceived as important in managing their COPD. These activities assumed such importance that they became part of the meaning of self-management, similar to the invoking of bodily symptoms in their meaning of COPD, as the findings in the first category suggested. Their comments pointed to self-concepts such as self-tailoring, self-awareness, self-acceptance and self-reliance, underscoring the importance of the self in self-management, a concept noted by others (Walker et al. 2003). Acceptance of limitations was also identified and has not been widely reported in the literature.

Self-reliance was acknowledged by this group as integral to self-management, and does not appear to have been reported in the literature. For these people, self-reliance suggested making informed choices, considering personal needs and ultimately acting upon their decisions. In this way, I suggest that participants in this study were identifying some of the elements of a participant-centred approach relevant to them, that is, informed decision-making with respect for participant preferences.

While they had referred to the value of action plans, participants did not allude to these when asked what self-management meant to them. This could be because for many people consciously setting action plans and then problem-solving around issues that arose appeared to have been a new experience. However, during the interviews the majority of participants overwhelmingly recognised the value of setting goals and implementing action plans, reinforcing the concept of these as core self-management skills, as discussed in *Chapter Two*.

7.4 A 'Shared' Engagement

Our aim in offering the CDSMP to patients with COPD is to help them attain their best possible health (medical, emotional, social and spiritual wellbeing) by helping them to develop or refine skills for managing the impact of COPD on their lives, that is, to facilitate self-management. (See *Chapter One* for a discussion relating to health.) Our aim in evaluating supervised exercise as an intervention was to ascertain if this is a necessary adjunct to the CDSMP offered in our hospital.

As I have mentioned previously, much of the self-management literature is directed toward reporting the outcomes of health behaviour change or maintenance flowing from participation in the CDSMP. Similarly, the cardiopulmonary rehabilitation

literature largely reports the outcomes of exercise in terms of physical or physiological parameters (Bestall et al. 2003; Grosbois 2001; Lacasse et al. 2004; McKenzie, Frith & Burdon 2003; Miyahara et al. 2000). The relationship between exercise and self-efficacy for exercise (walking) has been investigated by others (Bailey & Jackson 2003; Belza et al. 2001; Berry et al. 2003; Davis et al. 2006; Kaplan et al. 1994). However, little has been reported in the COPD or CDSMP literature concerning the experience of supervised exercise. Hence it is difficult to know if the traditional approach to healthcare interventions, such as supervised exercise, is addressing participant needs and facilitating behaviour change. How do we know if what is delivered is addressing the needs of the participant as viewed by them unless we listen to their voices? This research has attempted to understand the experience of the CDSMP and supervised exercise from the participant perspective, identifying what enables behaviour change and what might pose a barrier.

As all participants attended the CDSMP, it is impossible to isolate any influence this interaction may have had on the experience of those randomised to the exercise intervention. Therefore, my discussion points to the experience of both, noting similarities and differences, but makes no attempt to attribute causal mechanisms of the one at the expense of the other.

Age might have been expected to influence how people developed ways of managing life with COPD, in that there is a view that older people have experienced hardship and, as a result, developed ways of coping in adversity (Pound, Gompertz & Ebrahim 1998). For some people, loss of physical capacity was accepted as a 'biographically anticipated' event (Lawton 2003). However, for others, life with COPD was met with frustration and was not seen as a partner to ageing, an observation in keeping with others (Hansen, Walters & Wood Baker 2007). How people managed this changed life and whether or not they saw it as a 'biographical disruption' (Bury 1982) seemed to be influenced more by their sources of motivation.

Participants who relied on sources of external motivation appeared at times to struggle to cope and retain a sense of value (Bury 1982). They expressed frustration and uncertainty, indicating that life had been catastrophically disrupted. They frequently used phrases such as, 'I know what I should do, but...'. This was in direct contrast to those who recognised what they 'could do, and...', suggesting they were

more internally motivated. Although people who appeared internally motivated may also have experienced disruption of 'taken-for granted assumptions' (Bury 1982), there was a sense of evolving in a positive way: a changed life rather than a disruption. Perhaps a focus on abilities rather than losses during the CDSMP or supervised exercise facilitated or enhanced adaptations that people were already making. The following discussion highlights 'shared' or similar motivational influences acting across the CDSMP and supervised exercise sessions.

7.4.1 Social Benefits

Participation in the CDSMP and supervised exercise sessions is a group social experience. The psychosocial processes and motivational influences emerging from these data emphasise the overlap between the sociological and psychological literature noted by others (Bury, Newbould & Taylor 2005). Most participants attending the sessions spoke positively about the experience of identification that served to lessen the stigma of breathlessness and decreased physical ability as participants noted that this was 'normal' for people with COPD. This is in direct contrast to the suggestion that people with chronic conditions limit contact with similar others in an attempt to 'normalise' their experience in comparison to the prevailing social norms (Royer 1995). However, limited support for Royer's research is provided by the withdrawal from the programme of one participant who then agreed to be interviewed. This participant did not identify with, nor wish to be identified with, any of the people who were participating in the programme.

Downward social comparison was a process in which most interviewed participants engaged during supervised exercise and the CDSMP. For most people, this appeared to bolster self-esteem. Downward social comparison also represents a mechanism whereby individuals maintain perceived personal control in the face of increasing bodily limitations (Schulz & Heckhausen 1996). This is an important consideration for these participants with COPD who face a trajectory of increasing losses to both the body and the self. Their actual control over the progression of their COPD may be minimal, but if their perceived control is high, the literature suggests they are likely to experience better psychological health (Brown 1998d).

Nancy (C) engaged in upward social comparison with respect to knowledge and education and this served to increase her perceptions of low self-worth, causing her

to curtail her interaction with the group during the CDSMP for fear of embarrassment (Buunk et al. 1990). Nancy was the only person interviewed who spoke about this. However, as not all participants who attended the CDSMP were interviewed, there could be more who felt similarly; leaders need to be very aware that some people may not benefit from the 'sharing of ideas' format generally accepted as being a positive experience. No participant data concerning supervised exercise suggested the use of upward social comparison.

Many participants were encouraged to pursue their goals, being motivated by the successes of those they perceived to be like themselves, pointing to the influence of role models (Bandura 1986). This was evident in the CDSMP and the supervised exercise sessions where participants encouraged one another, and were encouraged by the accomplishments of others with COPD.

Most participants actively sought each other's company during the CDSMP and supervised exercise. However, as I noted in the findings, identification was not always mutually positive, and leaders need to be competent at recognising and managing negative experiences such as potential harassment and interpersonal differences.

I was interested to hear whether or not participants identified with the leaders of the CDSMP, as we are both health professionals and the CDSMP was initially designed to be facilitated by trained peer leaders, that is, non-health professional people with chronic conditions (Lorig 1982; Lorig, Sobel et al. 1999). However, as the findings of this study reveal, this was not a concern. Participants identified with me as someone else with a breathing problem (asthma), and knowing that my co-leader (a respiratory nurse) and I had experience and understanding in working with people with breathing problems was seen as a strength. These comments lend support to an earlier study of Kate Lorig and colleagues who found that there was little difference in outcomes regardless of whether health professionals or volunteer peer leaders facilitated the CDSMP (Lorig, Sobel et al. 2001).

7.4.2 Optimism and Perceived Personal Control

Some participants like Simon (C) and Peter (C) engaged in recognised self-management behaviours of problem-solving, and setting positive plans to manage

their lives with COPD prior to participating in the CDSMP, suggesting an optimistic approach to their lives (Brown 1998d). The data suggest that interaction with the CDSMP reinforced the optimism of those with this disposition and began to instil a sense of optimism and control in others. Optimists are purported to have a belief in their abilities to achieve their goals (Brown 1998d). In other words, they have robust self-efficacy for the chosen behaviour (Bandura 1986) and, as they complete action plans towards achieving their goals, their sense of perceived personal control over the behaviours in question increases (Chipperfield, Perry & Menec 1999).

I must reiterate that this positive observation was not the situation for all participants. There were some, particularly those whose self-presentation involved pre-emptive excuse making, who did not appear as optimistic as others (Brown 1998b). The inability to complete their action plans undermined their self-esteem. As Bandura has stated, success at achieving one's goals builds resilient self-efficacy, but failures undermine it, especially if one's sense of efficacy is still being established (Bandura 1994). Failing to complete action plans and attain goals suggests a lowering of perceived personal control. These participants responded with self-blame and feeling bad about *themselves*, supporting Brown's cognitive explanatory model of emotional distress for people with low self-esteem (Brown 1998c).

It is true that not all programmes suit all people. However, I restate my concern: as leaders and as health professionals in other arenas, we need to be vigilant that in encouraging the people with whom we work to set action plans, we do not heighten their perceived lack of personal control over their health, undermine their self-esteem and add to their difficult emotions. It behoves us to eschew stigmatising labels such as 'non-compliant' and to listen to the language our patients use such as 'I know what I should do but...', and to focus on what, if anything, they are currently doing to manage their health and then explore ways of facilitating further behaviour change.

7.4.3 Supervised Exercise

Those who advocated supervised group exercise reported being comfortable with people perceived as similar to themselves with respect to age group and condition, supporting the work of Biddle (Biddle 1994) who noted that older people referred by their doctor to an exercise group preferred to exercise with other older people. The

influence of role models is one of the acknowledged elements involved in the development of self-efficacy (Bandura 1986, 1994).

Self-monitoring of physiological parameters during the supervised exercise sessions allayed fear by allowing interpretation of signs and symptoms. Some participants found it preferable to learn the exercises in a supervised setting, suggesting low self-efficacy for initiating exercise when one has COPD. Participants attending the supervised exercise sessions learnt that it was not exercise per se that is to be feared, and by reinterpreting signs and symptoms and learning what is 'safe', self-efficacy for exercise may have been enhanced (Bandura 1986, 1997).

Seemingly self-efficacious participants like Simon (C) or Peter (C) suggested that others who were not as 'confident' might benefit from our approach to supervised exercise and develop an increased perceived physical capability. In this way self-efficacy might be enhanced, an important consideration as people with COPD who have robust self-efficacy for physical activity (measured by treadmill walking) are more likely to be physically active and to live longer (Kaplan et al. 1994). In our gym, we measure achievements in terms of individual progress. We value individual effort and assist people in learning from their attempts. This provides what is called a mastery climate that contributes to motivation, in this case, for exercise (Ames 1992). Participants supported our approach when they commented that attendance at our supervised exercise sessions motivated them to do more.

While the 'mastery climate' of our supervised exercise sessions may have contributed to motivation to exercise, the commitment to attend, with the expectation that some activity would take place, provided a necessary source of external motivation for some. They acknowledged that if such factors were not forthcoming this could then be used to excuse inactivity. By verbally announcing the commitment to another person, the likelihood of it being enacted is enhanced (Bandura 1986).

7.4.4 Action Plans

These data suggest that undertaking an exercise regime as part of an action plan during the CDSMP helped people to develop skills mastery for exercise (Bandura, 1986) whether or not they attended supervised exercise. Formal action plans were not set during the supervised exercise sessions, as I did not wish to confuse the

intervention with the CDSMP. When people undertake to walk for a set time on a treadmill or to perform other exercises, they are in fact formulating a plan of action for their exercise during the session. However, this was not approached in the formal manner of the CDSMP, which required participants to verbalise their intentions and precisely name the components of their action plan. While formal action plans were not set during the exercise sessions, participants commented that the interplay of mastering their exercise regime, receiving physiological and performance feedback and identifying with others in a supportive environment facilitated the development of their 'confidence' to undertake physical activity. This points to the development of self-efficacy for exercise.

There have been suggestions from others that those who struggle with action plans are not yet 'at an action stage' for that behaviour and that the CDSMP is only suitable for those who are ready to take action (H. Lidner, pers. comm., May 10th 2005). While being mindful that some individuals are forming an intention to adopt behaviours and some have adopted the behaviour, I suggest that offering a stage-based intervention according to the transtheoretical model of change (Prochaska 1984) is not appropriate for the CDSMP. Rather, participants select that which is applicable to them from a programme that seeks to mediate health behaviours and to provide participants with the tools to do this: that is, to self-manage their health. Facilitating the development of self-efficacy — helping people to develop a belief in their ability to modify their health behaviours during the programme — is one avenue to achieving this aim, rather than offering a stage-based intervention.

In my research, exercise was the behaviour being investigated, and those who appeared to rely on external motivation struggled most with setting formal action plans for exercise. However, by helping individuals to recognise that as they undertook exercises in our gym they were actually following a plan, they appeared to develop more confidence in their ability to exercise. These data suggest that health professionals need to be mindful that some people have different sources of motivation, and to orientate their approach accordingly. For example, exploring what the person is currently doing with respect to physical activity, discussing how exercise can be incorporated into the day and monitored, forms the basis of a plan without the individual having to first volunteer this information in a formal way.

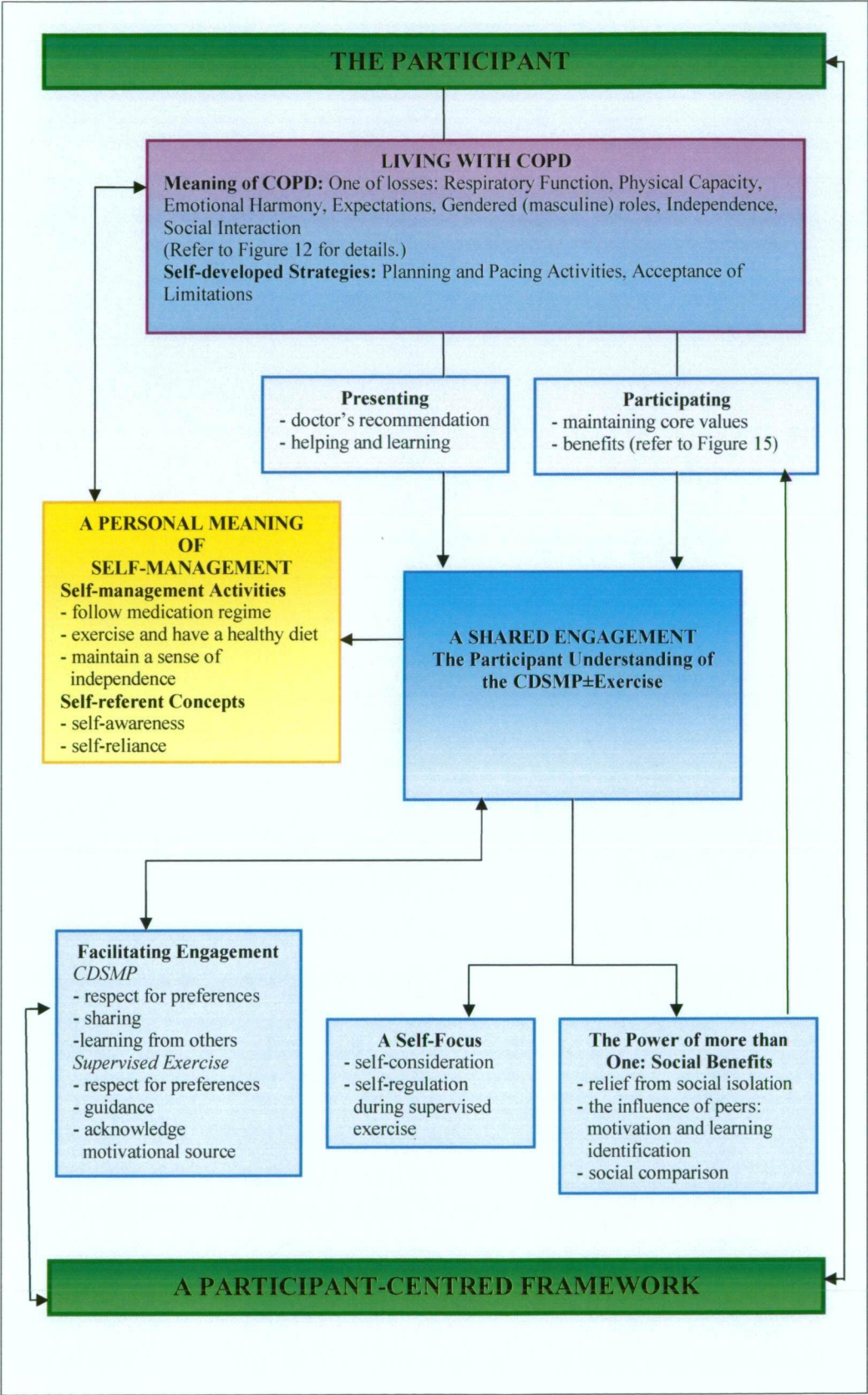
Adopting exercise is a complex process and as the participants in this study demonstrated, account must be taken of self-perceptions, self-presentation and motivational sources.

7.5 Toward a Participant-Centred Framework

A focus on, and respect for the participant and working toward attaining what is important to them is a strength of the CDSMP and the way we have offered the exercise programme at our hospital for more than a decade. As I have noted earlier, a participant-centred approach is not new. Indeed, a model of care for people with chronic conditions, the chronic care model, advocates the patient as central in their care (Wagner et al. 1999). As self-management approaches are situated within the patient-centred framework of the chronic care model, it is assumed that the CDSMP shares this framework. This has not been articulated, nor has a participant-centred approach been discussed in the limited qualitative enquiry concerning the CDSMP or in the exercise arena.

This thesis suggests that a participant-centred framework underpins the CDSMP and our supervised exercise sessions, linking the experiences and pointing to the value of such a framework for future interventions. This is illustrated by the conceptual map in Figure 17 below. I will discuss this framework further below, drawing upon current literature to support or dispute the proposal.

Figure 17: The Lived Experience



Von Korff et al. (1997) defined participant-centred approach as ‘collaborative management’: both the person with the condition and healthcare provider work in partnership towards mutually identified goals, with a shared understanding of the roles, responsibilities and skills of each other. Such a partnership wherein the expertise of the health professional and that of the patient is jointly recognised and valued has been referred to earlier as a ‘meeting of experts’ (Tuckett et al. 1985). The concept of ‘expert patients’ at the ‘centre’ of their own care (Clark 2003; Lorig 2002) and working in partnership with health professionals is an ideal increasingly espoused in the literature (Holman & Lorig 2000; Tattersall 2002).

The participants in this study did not refer to themselves as ‘experts’. Rather, during the CDSMP or supervised exercise sessions, they valued being guided, having their preferences with respect to target behaviours or exercise modalities sought, choices respected and sharing in decision-making rather than being taught and directed, as Ben (I) clearly articulated. In this approach the emphasis shifted from someone who was told what to do and to whom ‘things happen, to being a “doing” actor who makes things happen’ (Kelly & Field 1996, p. 245). Thus participants could be actively engaged with the health professional in structuring their exercise regimes during the supervised exercise sessions or in adopting or maintaining health behaviours as they developed self-management skills such as action planning during the CDSMP. A sense of being an actor who could ‘make things happen’ suggests self-efficacy for the target behaviour, and with it enhanced perceived personal control.

This observation is in direct contrast to recent qualitative research which concluded some health professionals were loathe to relinquish control and a former role of expert decision-maker (Paterson 2001; Thorne, Nyhlin & Paterson 2000). Findings of other research suggested that nurses in particular felt threatened by the ‘expert’ patient and were limited in their capacity to meet the needs of such patients (Wilson, Kendall & Brooks 2006).

The participant experience described in this thesis is also dissimilar to other interactions described within some traditional rehabilitation and exercise programmes. I am aware that this is the participant perspective only, which is what I sought to understand. Participants voiced frustration at a lack of explanation, being

disregarded, and being 'told what to do'. Their sense of being a 'causal agent' in their own healthcare appeared to be minimal, and they responded angrily (Kelly & Field 1996).

Perhaps the positive experience of the participants in this study reflects the training of the CDSMP leaders who are cautioned against offering advice and solutions to questions before allowing the participants to share their knowledge, and experience problem-solving themselves (Lorig, Gonzalez & Laurent 1999). In this way, as suggested by others (Stewart 2001), the participant 'drives' the degree of information they want or the degree of 'shared decision-making'. The healthcare professionals leading the CDSMP must tailor their responses to the individual needs of the participant.

The positive experiences may also reflect our practice in the exercise sessions, especially seeking the views of participants and what is important to them, as Ben's comments attest. We actively listen and offer choices, guiding participants as to the appropriate exercises for their COPD and health in general: we offer a 'menu', not a mandate. We respect the knowledge they have of their own bodies and we take this into account when making decisions with them concerning their exercise regimes. We collaboratively define the exercise regime, recognising that ultimately they will be exercising unsupervised at home. As I noted earlier, we value individual effort and our participants are assisted in learning a suitable exercise regime by feedback from their exercise performance, as well as being given guidelines for physical activity. In this way, I suggest that the mastery climate generated results in enhanced perceived personal control over their exercise regime.

The above discussion does not only point to a need for a more systematic participant-centred framework supporting the CDSMP and supervised exercise sessions; it also suggests that within such a framework participants may experience enhanced perceived personal control, of which self-efficacy may theoretically be a mediator.

The discussion also provides support for elements of a participant-centred approach reported in the literature. In particular, this research suggests participants valued enquiry as to their preferences, ideas and expectations. This has been suggested as a competency for health professionals in order to engage in shared decision-making

(Godolphin, Towle & McKendry 2001; Weston 2001). It is interesting to me that participants did not use terms appearing in the literature such as 'collaboratively defining problems' (Von Korff et al. 1997), or working towards 'mutually defined goals' (Toop 1998) when describing their experiences of the CDSMP or supervised exercise. Perhaps in exploring preferences, problems might be defined. They requested the right of choice, especially with respect to supervised exercise, a right recognised by others (Aroni et al. 2003). Perhaps in 'choosing', goals may also be defined. These elements and how they are perceived by participants would be worthy of further research in arriving at a meaning of participant-centred healthcare from a participant, as well as a health professional point of view.

No participant alluded to informed shared decision-making, a pillar of participant-centred care as defined by academic authors in the literature (Godolphin, Towle & McKendry 2001; Stewart 2001; Toop 1998; Weston 2001). However, they sought additional knowledge relevant to their needs, supporting an element identified by others (International Alliance of Patients' Organizations 2006; Stewart 2001). Having preferences defined and decisions arrived at with guidance suggests informed shared decision-making. This implies good communication skills and working in partnership, both of which have been identified as important by participants in other qualitative research (Little et al. 2001).

Descriptions of these interactions from the participant viewpoint and from the qualitative research referred to above also suggest the need to explore professional practice. Health professionals cannot be expected to provide care and facilitate self-management under a participant-centred framework if they are unaware of, or lack training in the requisite skills; are unaware of sources of motivation; and are unacquainted with self-management of chronic conditions. Training in applying motivational interviewing techniques during interactions with patients, exploring goals and setting action plans are skills incorporated into other self-management interventions striving toward a participant-centred approach (Battersby et al. 2003; Kelly, Menzies & Taylor 2003; Lidner et al. 2003). It is beyond the scope of this thesis to explore health professional practice or to make extensive recommendations. However, the data from these participants suggest that such an investigation would be worthy of undertaking.

A range of traditional or 'self-management' programmes have resulted in improved health outcomes for people with a number of chronic conditions such as COPD. This suggests that people with chronic conditions benefit from such interactions, which may be refining or adding to their existing skills. While others concluded the most effective intervention or essential elements have yet to be determined, a participant-centred approach was not mentioned in these reviews (Barlow 2002; Weingarten et al. 2002). However, in their extensive review of the literature, Wagner and colleagues (1996) had earlier concluded that chronic disease management models that included patients as partners with health professionals, addressing the needs and main problems according to the patient, were successful — whether the intervention was delivered in a group, individually, or by computer. My study supports the conclusions of Wagner et al. (1996). It suggests that participation in a participant-centred intervention (for example, our supervised exercise programme or the CDSMP) may be an important factor in helping people to develop, refine or maintain already effective self-management skills, enhancing perceived personal control over living with COPD.

In addition, I suggest that the participant-centred approach provides a supportive framework that acknowledges the participant as a whole person, thereby contributing to the success of interventions by adopting this approach. Others in the field of psychotherapy have suggested that the complex milieu of resources defining a participant may contribute up to 40% of the improvement following an intervention (Miller, Duncan & Hubble 1997). If this observation can extrapolate to other interactions, it is fitting for the health professional to enquire as to the strategies a person has developed, their environmental and psychosocial supports, how they define their condition and to ascertain motivational influences. In this way, the health professional is situated to work with the participant, building upon strengths in a collaborative manner to assist in managing life with COPD.

7.6 *Qualitative Study Limitations*

There are limitations to this qualitative arm of my study. The majority of participants had attended four or more sessions of the CDSMP. I cannot therefore imply that these data are representative of those who had attended fewer sessions. Similarly, participants were those with a primary diagnosis of COPD referred following a

medical appointment. Those who do not have COPD or such medical contact might respond differently. Participants were interviewed only once due to the time constraints of the study. How they would perceive the interaction in the longer term is unclear. These issues are suggested as the subject of future research.

A further limitation is that the research focused on participants only. A focus on participant experience was not to deny the pivotal role of family and carer influence on managing long-term health conditions (Clark, Gong & Kaciroti 2001). The acknowledgment of family and carers in the management of chronic disease points to the wider social context of the healthcare system and the community within which it is situated. This broad focus is espoused by the chronic care model, the ideal of which is patient-centred health care as noted above (Wagner et al. 1999). How these influences mould the participants' responses to healthcare interactions such as the CDSMP with or without supervised exercise would also be the subject of future research.

7.7 Implications for Healthcare

The preceding discussion highlights implications for healthcare. For clarity I will follow the order of the discussion, making suggestions for health care interactions.

First, participants in this study defined COPD with reference to their bodily experiences, rather than in anatomical or physiological terms. Health professionals will strengthen a partnership and learn much about which symptoms are of greatest importance to the people with whom they work by listening to their narratives.

Second, many self-management strategies were developed in response to participants' changed lives with COPD. This is an important observation. By first enquiring as to how participants currently manage their COPD (or other long-term health condition), health professionals may offer positive reinforcement of current health behaviours or effective strategies, while areas requiring attention may be collaboratively addressed.

Third, in a meaning of self-management these participants referred to COPD-specific health behaviours and to self-referent concepts. This again underscores the importance of health professionals acknowledging what people already do to self-

manage, how COPD affects how they think and feel about themselves and building upon this together.

Fourth, taking part in the CDSMP with or without supervised exercise served to reinforce, refine or contribute to participants' self-management skill base, especially the formal setting of goals and action plans. The process of action planning addresses participant preferences, an important element defined by these participants. Health professionals would benefit from training in facilitating this process as a step towards participant-centred healthcare.

The fifth point relates to supervised exercise. Participants overwhelmingly recommended the addition of supervised exercise to patient education programmes such as the CDSMP. Their comments suggest a re-evaluation of the delivery of exercise interventions. They urged us to consider their preferences. They welcomed guidance and facilitation, and eschewed didactic instruction with respect to exercise regimes. Above all, these participants wanted to be offered a choice of attending supervised exercise or of following a home-based programme, thereby allowing them to accommodate the impact of COPD on their lives. This suggests that one approach does not suit all individuals. This has implications for the CDSMP, which does not have a supervised exercise component, and for the more traditional cardiopulmonary rehabilitation, which usually includes supervised exercise: neither approach offers a choice. Future research could investigate the attendance at supervised exercise sessions and evaluate the effectiveness if such a choice were offered.

Sixth, the participants' perspective of other more traditional approaches to healthcare interventions suggests the need for analysis of health professional practice and, if required, the provision of training in a participant-centred framework and self-management. Education and training of the person with the chronic condition cannot be effective without education and training of those who deliver the intervention. With appropriate training, health professionals are in an ideal situation to promote active involvement of people in managing their chronic conditions whether this is during individual appointments, at bedside consultations, with telephone follow-up, or with computer-assisted feedback, in an institutional or community setting.

7.7 *Conclusions from Findings*

The forgoing discussion suggests a participant-centred framework as the underpinning structure of our supervised exercise sessions and the CDSMP. This thesis continues a line of empirical support for the seminal work of Wagner et al. (1996) and emphasises that we must listen to the voices of our participants. A participant-centred framework is proposed as a basis for a continuum of care in all healthcare interactions. Within this framework, interventions should be tailored to individual preferences. In arriving at these conclusions, I have drawn upon the sociological, psychological and, to a lesser extent, the medical literature, emphasising the complexity of life with COPD.

This study has highlighted the need to monitor individual responses to our interactions and evaluate interventions with an awareness of the different motivational orientations and preferences people may have. Participants recommended supervised exercise as a partner to the CDSMP, with the caveat of being able to choose.

The findings have indicated that motivational influences act across interventions, suggesting support for the construct of self-efficacy as a mediator of behaviour change or maintenance, and pointing to the pivotal role of perceived personal control in a life of ongoing restrictions. Perceived personal control does not appear to have been measured as an outcome of the CDSMP or exercise sessions. I suggest that such an enquiry may yield valuable insight into the effect of these interventions. In addition, a participant-centred approach may serve as the framework for enhancing perceived personal control. What such a framework might entail is presented in the following chapter, *Chapter Eight, Conclusions and Implications*.

8

CHAPTER EIGHT:

CONCLUSIONS AND IMPLICATIONS

8.1 Introduction

This thesis sought to investigate our clinical practice of offering the CDSMP, which does not include supervised exercise, to people with COPD instead of traditional cardiopulmonary rehabilitation. This is at a time when models of chronic disease management are being explored and adopted and when supervised exercise is recommended in the COPD management guidelines. There were two main research questions, the first of which requiring quantitative methods of enquiry, ‘What would be the benefits, if any, of including supervised exercise with the CDSMP for people with COPD who are referred for cardiopulmonary rehabilitation?’. The second qualitative research question was, ‘What is the lived experience of people with COPD who attend the programme with or without supervised exercise?’

These questions were important to me, as the benefits of regular exercise for people with COPD are widely acknowledged, also because the CDSMP purports to provide people with self-management skills to adopt health behaviours such as exercise. This is supported by some quantitative studies reporting an increase in self-reported exercise following programme participation. There is also limited research detailing the subjective experience of participants attending the programme and this was also important to understand if behaviour change is to be achieved.

A review of the literature highlighted the dearth of research concerning the addition of supervised exercise to the programme for any group of people, both with respect to quantifiable outcomes and qualitative findings. I sought to inform our clinical practice by quantitatively measuring the effect of supervised exercise with the

CDSMP and contextualising and enriching the outcomes by using qualitative enquiry to learn of the participant experience.

Mixed methodology was used since the quantitative measures provided valuable information about the effect of supervised exercise on a number of exercise-related outcomes and breathlessness but they could not be expected to explain the meaning of self-management and the inclusion of exercise as defined by the participants. In addition, neither could they be expected to alert us as to the motivational orientations and individual preferences of the participants who undertook exercise. The qualitative enquiry illuminated these issues, suggesting a broader finding that has been conceptualised as a framework for a participant-centred engagement for healthcare (PCEH). The findings from this research suggest that this approach will be critical to understand and refine interactions between those we seek to help. Such a finding has implications for future research as it would, in turn, need to be evaluated. These points are discussed later in this chapter. However, it is first important to provide a synopsis of the quantitative results and qualitative findings and point to implications for clinical practice and future research.

8.2 Synopsis of Quantitative and Qualitative Findings

In drawing together the findings of the quantitative and qualitative research, this thesis has provided evidence on the following areas of enquiry that will be addressed further in a discussion of implications for healthcare and future research :

1. The effect of supervised exercise

- Supervised exercise with the CDSMP is not necessary to improve physical capacity for people with COPD.
- The increase in distance walked was small compared with other studies in the COPD-related literature, pointing to the need for further investigation in this area, addressing variables such as the frequency of exercise and exercise self-efficacy as ways of gaining a greater improvement. Whether this small increase is functionally significant is not known, and more research is needed to determine this.
- Supervised exercise with the CDSMP is not necessary to gain small improvements in increased adoption of exercise, physical function, role

physical and role emotional aspects of quality of life, exercise self-efficacy and self-management behaviours.

- People attending supervised exercise sessions undertook moderate exercise more frequently and for longer duration, although minimum weekly recommendations were not met by the majority. They also experienced less breathlessness and improved physical activity component summary of quality of life compared with those who attended only the CDSMP. Further research is needed in this area to address ways of targeting exercise so minimum recommendations are achieved.
- Frequency of weekly exercise emerged as a variable requiring further investigation. My research indicates that frequency should be targeted for people with COPD. Home exercise programmes should be agreed upon and encouraged to increase exercise frequency.
- The mode of exercise supervision deserves further investigation. Group-based supervised exercise is preferred by some people, but not seen as essential by all.

2. *The lived experience of the CDSMP±Exercise*

- People referred to COPD in terms of its impact on their lives, developing self-management strategies and a personal meaning of self-management that they brought with them to the interaction.
- Enablers and inhibitors to attendance included, but were not limited to:
 - doctor's recommendation as a powerful enabler to enrolment
 - core values of honouring commitment and reliability as enablers to continued attendance
 - 'programme unsuitability' as a barrier to enrolment in the CDSMP
 - being unwell as a reason for non-attendance at exercise or CDSMP sessions
 - not meeting expectations as a reason to withdraw for some, but counteracted by the core values of others.
- Barriers and enablers must be analysed in order to extend the reach of our interventions.

The findings suggested a broad conclusion, encompassing the above points and described below.

3. *Participant-centred engagement for healthcare*

A framework for participant-centred engagement underpinned and supported participants' interactions and health behaviours during supervised exercise and the CDSMP. Emerging from the qualitative data was the importance for this engagement of:

- eliciting and respecting participants' preferences, for example, with respect to mode of exercise or type of interaction
- the development of self-consideration
- setting goals and action plans to address these preferences
- acknowledging individual sources of motivation
- being alert to possible adverse psychological effects of interventions.

The proposed framework appears to be central to clinical practice and engagement with participants and because of its potency will be discussed further in this chapter. Having been illuminated by the qualitative findings, this framework would need to be tested to evaluate its elements, especially from the participant and health professional viewpoints, pointing the direction for future research. Participant-centred healthcare has been acknowledged in the literature for over a decade (Coulter & Ellins 2007; Gerteis 1993; Stewart 1995). My research moves the discussion in the literature forwards by considering the key elements for engagement.

8.3 *Implications for Practice and Future Research*

8.3.1 **Supervised Exercise With the CDSMP**

This appears to be the first study evaluating the addition of supervised exercise to the CDSMP for any group of people. My research has demonstrated that individuals with COPD do not necessarily need to attend supervised exercise with the CDSMP to gain small benefits in some areas. With or without supervised exercise, physical capacity significantly improved, the adoption of exercise was facilitated, exercise self-efficacy, self-management behaviours and the physical role and function domains of quality of life all increased. The addition of supervised exercise augmented these

effects. Those who took part in the exercise intervention undertook moderate exercise more often, for longer periods of time and experienced less perceived breathlessness. When all of the quality of life domains were accounted for, supervised exercise also had a greater effect on the physical component summary.

8.3.1.1 Suggestions for Future Research

There are considerations for clinical practice and future research:

1. These results have important implications for delivery of healthcare interventions of this type. Where the 6MWT is considered to be a gold standard for measuring the effect of exercise interventions (Lacasse et al. 2006), the additional cost of providing supervised exercise would not need to be borne by the health sector, if a small increase is functionally important. For people whose physical activities are restricted, small changes in capacity may be functionally important. As it was discussed in *Chapter Five*, clinical significance for change in 6MWT distance has been reported in the literature with reference to other individuals (Redelmeier et al. 1997) but not using self-referent values for people with COPD. Additionally, change in distance walked has not been linked with key functional activities defined by the individual, suggesting a much needed area of enquiry.
2. The importance of the frequency of moderate exercise and exercise self-efficacy and the association with the change in distance walked was shown in a multiple linear regression analysis. This result suggests that in clinical practice we pay particular attention to these parameters of exercise behaviour, making enquiry as to the frequency of exercise and confidence to exercise. In this way, those who have lower exercise frequency or who are less confident may be identified and appropriate management strategies discussed with the participant. Thus, the interaction moves from 'giving' an exercise prescription to negotiating an exercise plan, a feature of the participant-centred model implied by this research. Future research would investigate the effect of targeting frequency of moderate exercise and exercise self-efficacy on physical capacity.
3. The most likely explanation for the similar change in distance walked by each group and for the similar effect on adoption of exercise, exercise self-efficacy, self-management behaviours and the emotional and physical role and function domains of

quality of life is the behavioural basis of the CDSMP to which all participants were exposed. This enabled them to develop or refine self-management activities, especially setting exercise goals and action plans. The value to participants in this study of setting goals and action plans emerged from the qualitative data (*Chapter Six*). For most interviewed participants, the completion of these appeared to aid self-regulation of exercise and increase perceived personal control (Petersen & Stunkard 1989). Future studies would need to test this hypothesis before any conclusions could be drawn. Measuring perceived personal control may be an important outcome and may predict those who have better self-management skills and who adopt health-related behaviours.

4. Comments from some of the interviewed participants suggested that attendance at supervised exercise depended on the motivational orientation and preferences of the individual. There are individuals who benefit from group participation, as well as those for whom group engagement is not a preference. There are those who benefit from and are motivated by group processes of identifying with like others and learning from role models (Bandura 1986), social comparison (Buunk et al. 1990; Festinger 1954) and social interaction; or who benefit from fear reduction by monitoring physiological parameters and learning in a safe environment. Alternatively, there are individuals who appear to be internally motivated and are able to self-regulate exercise independently and do not require group support or supervision. Identifying motivational orientation and the preferred exercise interaction would be a first step toward engaging in a participant-centred manner, tailoring the mode of intervention delivery to the individual. This is a suggested area of future research.

5. The mode of supervision and the effect on health behaviours, including exercise, requires further attention and has implications for healthcare delivery. As discussed in *Chapter Seven*, participant comments suggested a re-evaluation of the delivery of exercise interventions. There are a variety of modes of delivery that could be explored and include face-to-face, using information technology, individual or group-based, self-directed or mentor-guided. In addition, participants may benefit from specifically targeting, recording, reviewing and progressing health behaviours such as exercise, tailoring it to their individual goals and to those activities known to

benefit people with COPD. If this were to happen, would the minimum exercise recommendations be met and by more people? Would physical capacity and exercise activity be augmented further? In my study, this did not occur. The reason for this was because in keeping with the CDSMP protocol, home-exercise was encouraged at one session only, and solely determined by the individual. The same may be true of other health behaviours that may need to be specifically targeted if the CDSMP is offered instead of traditional approaches. Research in this area is urgently needed to inform clinical practice.

8.3.1.2 Future Research Questions

The suggested research questions arising from this thesis are:

- What is the minimal clinically important difference for the 6MWT defined by self-referent comparisons?
- What is the association of participant-defined magnitude of changes in the 6MWT with distance walked?
- What is the association of key functional activities defined by the individual with the change in 6MWT distance?
- What is the association of participant-defined magnitude of changes in the 6MWT with functional activities defined by the individual?
- What is the effect on physical capacity of using, for example, daily electronic prompts, on frequency of moderate exercise and exercise self-efficacy?
- What is the effect of setting goals and action plans on self-regulation of exercise and on perceived personal control?
- What is the effect of identifying the motivational orientation and the preferred exercise interaction of individuals on their perception of participant-centred healthcare and on exercise behaviour?
- What is the effect of different modes of delivery (for example, face-to-face, using information technology, individual or group-based, self-directed or mentor-guided) with structured feedback on physical capacity and meeting the minimum exercise recommendations?

8.3.1.3 Recommended Revisions to the Study

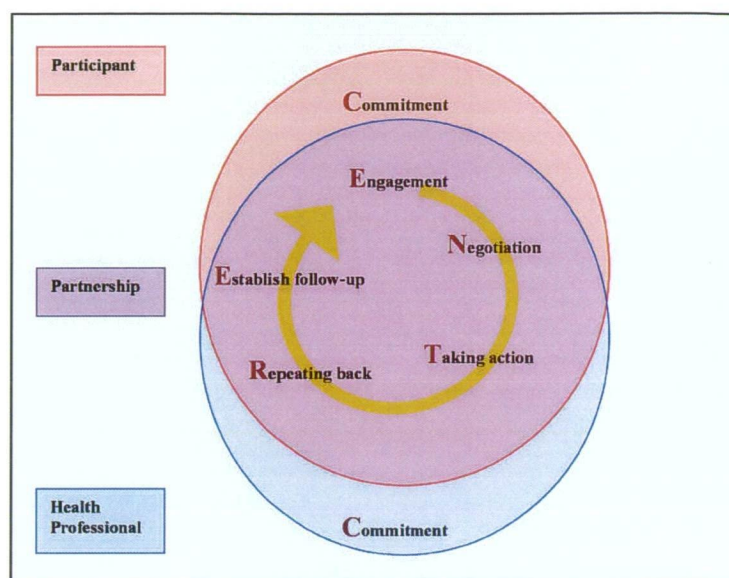
Should the study reported here be repeated in the future, there are some areas that would require revision. The recommendations are:

- Separate the intervention and control groups when participating in the CDSMP, maintaining the same leaders for consistency of delivery. Although every effort was made to prevent disclosure of the supervised exercise experience, I cannot be sure that participants did not discuss this.
- Analyse the practice/familiarisation walk data. Record the distance walked and time between it and the baseline walk. These data would add to the evidence for 6MWT protocol.
- Include an objective measure of daily physical activity, such as an accelerometer. These data would provide valuable information as to any associations with self-reported exercise in this study.
- Record action plans set by participants. The defined activities, whether the plan was completed, and if not, barriers to completion and solutions to address the barriers could be analysed. These data would provide additional information about exercise behaviour if plans had been set to address this activity.
- Include a condition-specific HRQoL questionnaire in addition to the SF-36v2. Although the SF-36 v2 has been found to be as responsive as the condition-specific SGRQ (see *Chapter Three*), a condition-specific questionnaire has not been used in conjunction with the CDSMP for people with COPD.

Regardless of delivery mode of exercise or other interventions, the implications arising from the above conclusions suggest that a participant-centred engagement for healthcare should underpin the interaction. The qualitative findings revealed the benefits of self-consideration in achieving individual goals, and of engaging in a process that was focused not only on addressing health-behaviours, but also on emotional and social functions, in a context of what was important to the individual. It appears that a non-didactic style of interaction is critical to engaging with

participants in healthcare interactions, and this will be elaborated upon as an element of a participant-centred framework later in this chapter.

Others (Stewart 1995) have reviewed the outcomes of what is widely called shared decision-making in the general practice literature and, more recently, patient-focused care (Coulter & Ellins 2007). The literature indicates that engaging the participant in their healthcare results in decreased psychological distress (Stewart 1995); improved participants' outcomes (understanding, health behaviour and status) and decreased use of health services (Coulter & Ellins 2007). The model I propose (Figure 18) supports the wider literature by advocating a partnership, with those we seek to help being the focus of the interaction. In particular, the proposed Participant-CENTREd Engagement for Healthcare model acknowledges the mutual expertise of both participant and health professional, recognising that each has preferences to be considered in arriving at decisions for care. The theoretical framework of *Commitment, Engagement, Negotiation, Taking action, Repeating back, Establishing follow-up (CENTRE)* is elaborated upon later in this chapter. Conclusions are drawn from this research about the features of such a participant-centred approach in clinical practice.

Figure 18: Model for Participant-CENTREd Engagement for Healthcare

8.3.2 The Experience of the CDSMP±Exercise

Emerging from the qualitative data was a picture of people who bring to healthcare interactions their own personal meaning of self-management and strategies to manage life with COPD. Meanings and strategies developed from, and were described in terms of, the impact COPD had on their lives. Such personal responses, although reported in sociological texts (Fagerhaugh 1993; Hansen, Walters & Wood Baker 2007), are not widely recognised in the literature pertaining to self-management interventions. Participants interviewed in my study defined self-management with reference to the self and the activities they undertook when living with COPD (*Chapter Six*). To these participants, self-management meant having self-reliance and self-awareness in order to arrive at acceptance of COPD and the limitations it placed on their lives; as well as adopting health-related behaviours in a self-tailoring context while maintaining a sense of independence in life.

The participants' meaning of self-management adds to the definition distilled from the work of others (Battersby et al. 2003; Clark et al. 1991; Corbin & Strauss 1988; Kralik et al. 2004; Lorig 2003) and described in *Chapter One*. My thesis proposes that self-management is a dynamic process incorporating an individual's capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-tailoring context to

deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains.

The experience of the CDSMP and supervised exercise augmented the focus on the self. For clinicians, this is an important consideration with implications for clinical practice. As it was discussed in *Chapter Seven*, by making enquiry as to a personal meaning of life with a chronic condition and what a person currently does to self-manage, health professionals are then situated to build upon this base, engaging in a participant-centred partnership with the person with the chronic condition.

However, not all of those referred wished to engage in the healthcare interaction offered, with many refusing an initial appointment. Programme 'unsuitability' was cited as a barrier and suggests the need for different modes of intervention, as noted earlier. Barriers need to be continuously assessed to extend the reach of interventions to people who want to participate. Additionally, programme flexibility is necessary when working with people who are likely to experience periods of poorer health likely to interrupt attendance. Procedures for follow-up of non-attendance need to be an integral component of service delivery, and the effect of such follow-up evaluated.

A doctor's recommendation was a powerful enabler to attending an appointment and subsequently enrolling in the programme. Ways of engaging with healthcare professionals in primary and secondary care need to be explored and evaluated. Working in partnership with medical practitioners and providing evidence as to why they should endorse interventions is imperative. Methods of facilitating the referral process from individual doctors should be explored, evaluated and implemented.

Most participants spoke enthusiastically of the positive effect stemming from their experiences, although the effects of the CDSMP and supervised exercise when measured mathematically may have been small. This seemingly contradictory finding points to the need to investigate interventions using mixed methods (Monninkhof et al. 2004). The primary aim of providing triangulation of the data by using mixed methods in my study was to provide a more detailed analysis of the effect of supervised exercise with the CDSMP than that afforded by either method alone (Brannen 1992; Hansen 2006). This aim has been achieved. To focus only on

the small changes shown by the quantitative data in this study would have risked not only denying the importance of the participants' story of their experiences (Bleakley 2005), but also denying the learning we as health professionals gain from those stories. My thesis points to the imperative of future studies exploring healthcare interventions by both quantitative and qualitative methods of enquiry. To do this as part of clinical practice would require the development of validated tools that are simple to implement and analyse, and which are not time-consuming in their administration. Health professionals may need to be trained in the use of these tools, the administration of which could become part of routine clinical practice.

The CDSMP did not meet the expectations of all participants, as evidenced by statements from some who withdrew or others who continued to attend despite not meeting their needs. Although most found setting action plans to be a positive experience, some found this difficult and struggled to maintain their self-esteem when not completing a plan was perceived as failure. This has very important clinical implications. We cannot assume that, at best, interventions are psychologically positive for all who attend; or at worst, they are benign. My study has revealed there is the small potential for some participants to feel psychologically worse off following a group-based programme, supporting an observation made by others (Dowson, Kuijer & Mulder 2004). We have an ethical responsibility as healthcare practitioners to do no harm. To improve service delivery and offer participant-centred self-management support, it is imperative to ascertain where interventions fall short of participants' expectations, to identify those for whom the experience may not be psychologically helpful and to address the concerns immediately.

The findings suggest a need for a framework of participant-centred engagement underpinning the CDSMP and supervised exercise experiences to guide clinical practice. While this approach is recognised in the self-management and general-practitioner literature (Elwyn 2006; Towle & Godolphin 1999; Von Korff et al. 1997), there is scant reference to it in the traditional cardiopulmonary rehabilitation body of work. The proposed Participant-CENTREd Engagement for Healthcare model (Figure 18) is central to the experience of my study, and I suggest, to clinical practice. It is discussed further in the following section, drawing upon the findings from the qualitative research.

8.3.3 Participant-CENTREd Engagement for Healthcare (PCEH)

A participant-centred focus of engagement is an implication for practice suggested by my research as critical for achieving health-related benefits in the lives of those we seek to help. My study suggests that this process is not concerned with ‘who knows best’, but rather with how the interaction between health professional and participant facilitates a consideration of self and the best possible behaviours to manage life with long-term health conditions. It is recognised that such interactions encompass more than self-management of chronic disease and that self-management encompasses more than undertaking health-related behaviours. Nevertheless, as exercise was the health behaviour studied in this research, the following discussion uses exercise as an example.

8.3.3.1 Philosophy of a Participant-Centred Healthcare Engagement

It is unrealistic to expect all facilities or all interventions to be able to fully engage in participant-centred care as suggested by the following framework. However, the philosophy of this engagement may be brought to any interaction between healthcare professional and participant and applied along a continuum of acuity to severity, in primary or secondary healthcare settings.

The six elements of Participant-CENTREd Engagement for Healthcare presented in this thesis (Figure 18) are defined in the context of a working model in Table 35. To embrace a participant-centred focus of care, first and foremost there must be *commitment* to the philosophy of a participant-centred engagement; one in which a partnership is forged between participants, families and carers, and health professionals, based upon mutual respect and consideration of individual background. In such a partnership health professionals and participants *engage*, mutually acknowledging the range of skills and experiences or expertise each brings to an interaction, respecting individual preferences and motivational level. Relevant information and skills training to aid self-management of health in general and the condition in particular is provided. This leads to definition of areas of individual and mutual concern as a prelude to *negotiating* goals to address these concerns. In the model (Table 35) participants are assisted to *take action* by developing action plans to achieve the goals. The main areas of concern and the action plan are *repeated back*

to ensure both health professionals and participant agree with and understand decisions made. As a final step, follow-up is *established* by mutual agreement.

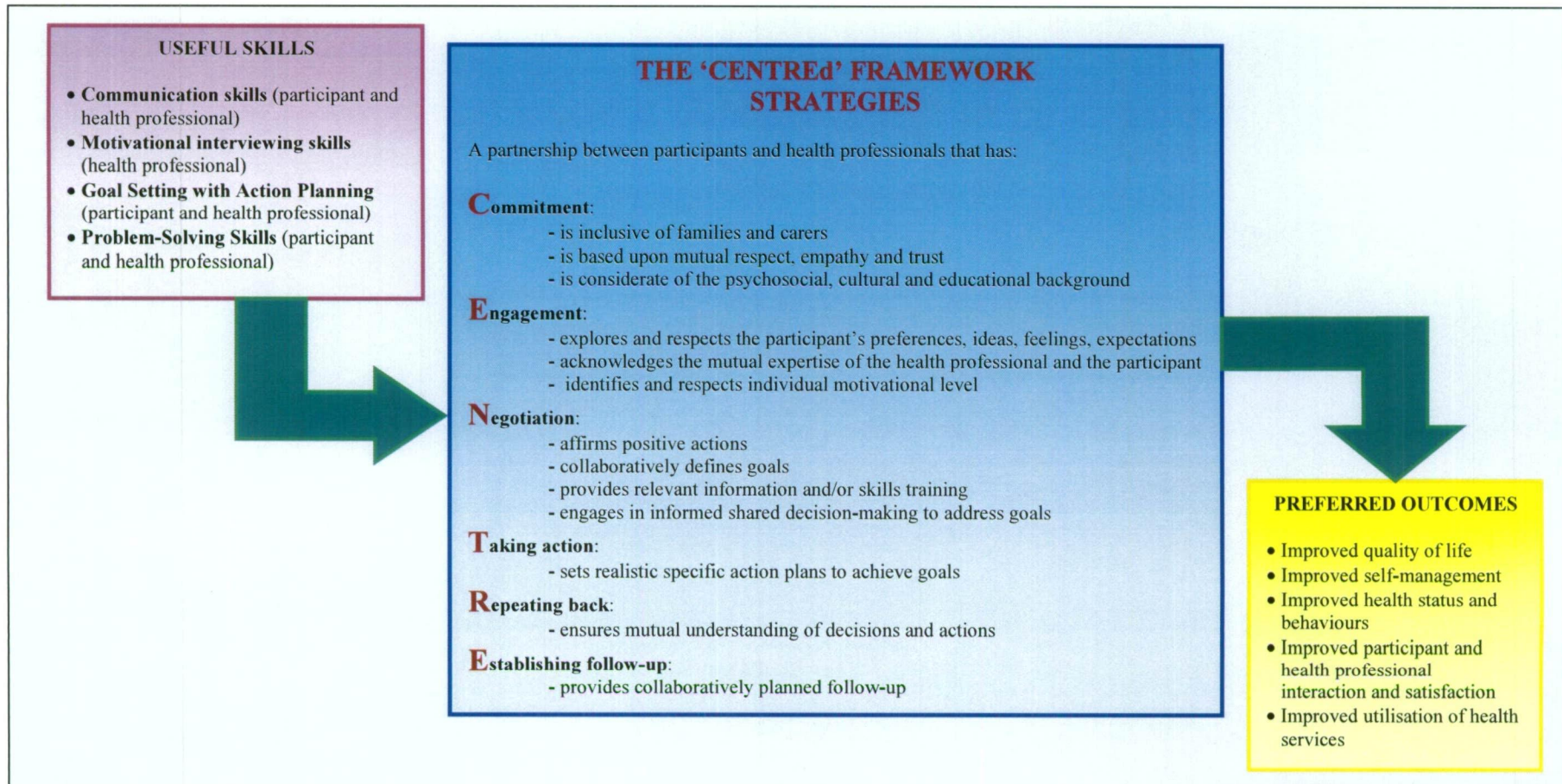
Table 35: Elements of Participant-CENTREd Engagement for Healthcare

CENTREd	MEANING
Commitment	Commitment to the ideal of a ‘partnership’, based on mutual respect, empathy and trust between participants and health professionals is fundamental to the philosophy of participant-centred engagement. The partnership considers the psychosocial, cultural and educational background of participants, their family, significant others or carers.
Engagement	The partnership explores and respects the participant’s preferences, ideas, feelings and expectations; acknowledges the mutual expertise of both health professional and participant and recognises his/her motivational level.
Negotiation	The partnership affirms positive actions, defines areas of mutual concern, engages in negotiation of goals and action planning to address these concerns, ensuring the provision of relevant information and skills to arrive at informed shared decisions.
Taking action to achieve goals	Specific action plans are set to address areas of mutual concern.
Repeating back	Both participant and health professional repeat back relevant information to ensure understanding and provide clarification where necessary.
Establishing collaboratively planned follow-up	The partnership mutually establishes and agrees to planned follow-up.

8.3.3.2 Framework for a Participant-CENTREd Engagement for Healthcare

The proposed model adds to the extant body of work by drawing together theoretical elements and fundamental skills for a participant-centred engagement, and suggesting evaluation and preferred outcomes. A methodological framework is presented in Figure 19.

Figure 19: Participant-CENTRED Engagement: Skills, Strategies and Outcomes



The expertise of professionals may influence the extent to which the elements of a participant-centred engagement may be applied. Therefore the PCEH framework is supplemented with a booklet (Appendix E) to assist health professionals reading this thesis who might ask for description of essential skills they require and how the elements of this engagement framework could be applied to clinical practice. The PCEH framework has implications for professional practice; therefore it is discussed in some detail in the booklet, with reference to my research. Finally, it is essential that this framework be tested in clinical practice. Suggested outcomes and measures are referred to and an evaluation tool presented in the booklet (Appendix E).

The proposed model of engagement may be brought to any healthcare interaction and its strategies applied according to the enablers and barriers relating to personal skills, to the facility and to the system within which that facility is embedded. The supervised exercise sessions and the CDSMP were strong in some of these components and lacking in others. Boundaries imposed upon the sessions were the inability to offer a choice of venue or flexible times. Additionally, negotiation or planned follow-up is not part of the CDSMP process, nor expected to be. However, the indications from the qualitative research were that during both supervised exercise sessions and the CDSMP many strategies suggested in the PCEH framework were applied. The implication is that this engagement points to enhanced perceived personal control, indicating a need for further enquiry in this area. The framework suggested by the qualitative research would now need to be evaluated by quantitative and qualitative means, from participant and healthcare provider perspectives.

8.4 *Summary of Conclusions*

This research demonstrates and emphasises the imperative of evaluating intervention programmes by both quantitative and qualitative methods of enquiry. In this way, objective high-level evidence is enriched by the participant experience, building theory, which in turn suggests theories that should then be investigated with quantitative methods. Outcomes of a participant-centred engagement that have not been measured in this research may include satisfaction with the engagement, personal control and improved healthcare utilisation. By listening to and acknowledging the voices of participants, the research interpretation also assumes a participant-centred focus.

This thesis comes to six main conclusions presented below.

First, supervised exercise does not need to be offered with the CDSMP to effect small improvements in physical capacity, increased exercise adoption, physical function, role physical and role emotional domains of quality of life, exercise self-efficacy and self-management behaviours. However, with the exception of the 6MWT distance, changes were not statistically significant, pointing to the need for further research in this area.

Second, supervised exercise confers additional benefit in that those who attended undertook moderate exercise more frequently and for longer duration, experienced decreased breathlessness and improved physical activity component summary of quality of life compared with those who attended only the CDSMP. However, the pre-test post-test improvement in exercise behaviour does not by itself provide evidence of the efficacy of the intervention. A study powered to detect a significant improvement in these outcomes is needed.

Third, the mode of exercise supervision and variables such as frequency of moderate exercise, exercise self-efficacy, specifically targeting exercise in action plans and the functional significance of a change in 6MWT distance deserve further investigation. The increase in 6MWT distance was small and did not reach the currently accepted minimal clinically important difference. In addition minimum recommendations for weekly moderate exercise were not met.

Fourth, group-based exercise was preferred by some but not seen as essential by all. There are some individuals for whom supervised exercise is necessary. To facilitate exercise for as many people as possible, it is recommended that a 'menu' of exercise options be offered within the constraints of the facility and professional expertise. As such, exercise should be recommended by health professionals and made available to individuals when enrolling in the CDSMP, allowing participants to choose what suits their needs, the severity of their condition and motivational sources upon which they draw when undertaking exercise.

Fifth, health professionals need to be alert to possible adverse psychological effects of interventions and to identify at-risk individuals. They also need to be aware of

situations where expectations are not met, to monitor this and address issues accordingly.

Sixth, it is suggested that interactions with individuals with long-term health conditions, such as COPD, would be strengthened by a participant-centred engagement committed to the ideal of a partnership wherein there is mutual recognition of the skills, knowledge and expertise both participant and health professional bring to an interaction. The effectiveness of interactions is enhanced if we recognise the meaning ascribed to conditions, the skills and motivational level people bring to interactions and the impact of the condition on the individual. In addition, this study revealed that fundamental to the engagement is a respect for the needs, preferences and choices of the individual. This leads to a sharing of informed decisions directed toward goals and completing agreed specified plans, which are monitored and reviewed during planned follow-up.

In closing, healthcare interactions encompass not only self-management, but support for delivering the interventions from the systems within which they are embedded, which in turn require support from the wider community and government policies. In addition, while this thesis had an exercise focus, it also revealed that self-management covers all aspects of health: medical, emotional, social, and spiritual and importantly, a sense of self. Moreover, many people have developed effective strategies for managing their health. The implications from these analyses led to a proposed Participant-CENTREd Engagement in Healthcare framework that acknowledges these points, providing a step toward supporting both participant and healthcare provider as they work in partnership to manage the impact of life with a chronic condition.

Finally, should supervised exercise be an integral component of the CDSMP? My research indicates not necessarily. With or without supervised exercise, small improvements, particularly in physical capacity, can be expected, although clinical significance was not reached. Attending supervised exercise appears to confer additional benefit with respect to exercise behaviour, and was seen as providing an essential motivating force for some. From my research, I recommend supervised exercise as an option with the CDSMP, discussing the benefits, risks and guidelines with participants, and offering a 'menu' of exercise choices that consider the

participant's needs and preferences. This research does not indicate that one hour of weekly supervised exercise must be an integral component of the CDSMP. However, the changes were small for both the CDSMP with supervised exercise, and the CDSMP only. This, with the lack of clinical significance of the changes warrants further investigation.

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APPENDICES

Appendix A: Information and Forms

A.1 Letter to Doctors

A.2 Participant Information

A.3 Chronic Disease Self-Management Brochure

A.4 Eligibility Assessment Form

A.5 Consent Form

A.6 Questionnaire: Cover Sheets and Demographics

A.6.1 CHAMPS Activities Questionnaire for Older Adults

A.6.2 Stages of Change – Short Form Questionnaire and Exercise Criteria

A.6.3 Exercise: Self-Efficacy Measure

A.6.4 Shortness of Breath Visual Analogue Scale

A.6.5 Short-Form 36 Questionnaire Version 2 (SF-36v2)

A.6.6 Partners in Health Scale

A.7 Objective Data Record Sheet

A.8 Supervised Exercise Record Sheet

A.9 Prompts during the Interviews

A.10 Thank-you letter

Notes:

1. The initial intent of this research was to recruit people with chronic heart failure as well as chronic obstructive pulmonary disease. However, as there were insufficient referrals for people with chronic heart failure, only those with chronic obstructive pulmonary disease were able to be recruited. The letters and participant information reflect this initial intent.

2. The Chronic Disease Self-Management Programme is known as the 'Self-Management for Wellbeing Programme' within the Royal Hobart Hospital where the research took place.

3. All participant information and questionnaires were written in font size 14. They are reproduced here in font size 10.

A.1 Letter to Doctors

//

Dear

Re PhD project (Helen Cameron-Tucker, Physiotherapist):

Comparison of the Chronic Disease Self-Management Programme plus supervised exercise (CDSMP-EX) with the CDSMP alone (CDSMP-Only) for people with Chronic Obstructive Pulmonary Disease (COPD) or systolic Chronic Heart Failure (CHF).

I am the coordinator of cardiopulmonary rehabilitation at the Royal Hobart Hospital and will be conducting this research. I am asking for your assistance by referring people with either **COPD diagnosed by spirometry**, or with **left systolic CHF, diagnosed by echocardiography**.

The CDSMP is a 6-week programme with sessions of 2.5 hours duration offered once per week. It is an interactive, supportive, group-based programme, catering for up to 15 individuals. It is run by pairs of trained leaders who have undertaken 20 hours of training. (In the Royal Hobart Hospital, health professionals have undertaken this training.) The leaders follow a highly structured manual. A course companion book, 'Living a Healthy Life with Chronic Conditions', is available for participants.

The CDSMP, known as the 'Self-Management for Wellbeing Programme' at the Royal Hobart Hospital is currently being offered instead of the usual rehabilitation programmes. Supervised exercise is not a component of this programme. **This research proposes to implement an exercise programme in conjunction with the CDSMP and to compare it with the CDSMP alone, using a randomised controlled trial approach.** A summary of 'Participant Information' is enclosed for your interest. The project has received Royal Hobart Hospital and ethics approval.

Those patients who do not wish to participate in the research, but who would like to attend a programme, will be referred to another programme. Relevant results of outcomes for any referred patient will be sent to you on completion of the programme.

Referrals. Please send referrals for the 'Self-Management for Wellbeing Programme' to me at the address indicated. **Would you please include results of spirometry or echocardiogram and date of test?** I will arrange an appointment and conduct the screening assessment for the study. I look forward to receiving your referrals.

Yours sincerely,

Helen Cameron-Tucker

Physiotherapist,

Department of Physiotherapy,

Royal Hobart Hospital,

Liverpool Street,

Hobart,

Tasmania. 7000.

Telephone: 6222 8571 (RHH) or 6226 4893 (Clinical School, University of Tasmania).

A.2 Participant Information

PARTICIPANT INFORMATION (SUMMARY)

You are invited to take part in this research project:

‘A COMPARISON OF THE SELF-MANAGEMENT FOR WELLBEING PROGRAMME PLUS SUPERVISED EXERCISE WITH THE SELF-MANAGEMENT FOR WELLBEING PROGRAMME ALONE FOR PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE OR CHRONIC HEART FAILURE’.

At the Royal Hobart Hospital we are offering the Self-Management for Wellbeing Programme, a programme for people with long-term health conditions such as Chronic Obstructive Pulmonary Disease or Chronic Heart Failure. This programme is designed to help you to become an active partner with your health professionals in managing your health. The programme itself runs over 6 weeks with one two-and-a-half hour session per week. (For this project there will also be a session for evaluation purposes before and after the programme, making it 8 weeks in total.) The programme is led by pairs of trained leaders. Helen and Lyn will be your leaders.

It covers the topics of Self-Management and chronic conditions, Making an Action Plan, Using your mind to help manage symptoms, Relaxation, Dealing with difficult emotions, Exercise and fitness, Better breathing, Dealing with fatigue, Healthy eating, Enduring guardianship and making your wishes for health care known, Communication, Medication usage, Making treatment decisions, Depression, Communicating with and working with the health care team.

There is no supervised exercise as part of the Self-Management for Wellbeing Programme. Therefore we would like to see if taking part in supervised exercise makes any difference to the people who attend the programme. To do this we need to evaluate the Self-Management for Wellbeing Programme with supervised exercise and without supervised exercise. If you agree to take part in this project, you will be randomly selected to take part in the exercise session or not. So some will attend a supervised exercise session during the same week of the programme (on a Tuesday OR Thursday from 11.00am to 12.00pm) and then everyone will attend the Self-Management for Wellbeing Programme (on a Tuesday from 1.00pm to 3.30pm.)

If you agree to participate in this project you will be asked to

- phase one of the project

- Complete questionnaires and do a 6-minute walk test as part of the evaluation (week 1). These questionnaires will be anonymous.
- Attend the Self-Management for Wellbeing Programme for 6 weeks (weeks 2–7), as described above.
- Attend an exercise session before the Self-Management for Wellbeing Programme if you have been randomly selected to do this, as described above.
- Repeat the questionnaire and the 6-minute walk test (week 8) as part of the follow-up evaluation.

-phase two of the project

- **We would also like to know what you think about the programme and exercise.** Therefore when you have completed the programme you will be asked if you would agree to being interviewed so that your opinion may be part of this project. If you agree, you will be contacted to arrange an interview time at a location of your choice. The interview will be taped and then transcribed, omitting any information which might identify you.

PARTICIPANT INFORMATION

You are invited to take part in this research project:

‘A comparison of the Self-Management for Wellbeing Programme plus supervised exercise with the Self-Management for Wellbeing Programme alone for people with Chronic Obstructive Pulmonary Disease or Chronic Heart Failure’.

This information sheet explains the research project to you. What is involved in this project is explained honestly and as clearly as possible so that you may decide whether or not to participate. Please read this Participant Information carefully. Feel free to ask any questions you would like to.

Once you decide to take part in the study you will be given a Consent Form to sign. By signing this form you agree that you understand what is involved in the project and that you agree to take part. If you choose to withdraw from the project, it will in no way affect your relationship with your doctor or other health care providers. You will be given a copy of the Participant Information and Consent Form to keep as a record.

Investigators

The Chief Investigators of this project are

- Dr Richard Wood-Baker, Director and Staff Specialist Respiratory Medicine, Royal Hobart Hospital
 - Dr Christine Owen, Assistant Dean, Faculty of Education, University of Tasmania
- The Research Nurse is.

- Lyn Joseph, Respiratory Nurse, Royal Hobart Hospital.

An Additional Investigator is

- Helen Cameron-Tucker, Physiotherapist, Royal Hobart Hospital and PhD student, University of Tasmania.

Assistants are

- Wendy Tilley, Physiotherapist and Maree Tennant, Physiotherapy Assistant, Royal Hobart Hospital.

Helen, Lyn, Wendy and Maree will be assisting you during the project.

Purpose of the project

This project is being undertaken to fulfil the requirements for a postgraduate degree (a Doctorate of Philosophy or PhD). The aim of the project is to **compare the Self-Management for Wellbeing Programme plus supervised exercise with the Self-Management for Wellbeing Programme alone** for people with Chronic Obstructive Pulmonary Disease or Chronic Heart Failure.

Who may participate in the project?

We welcome you to participate in this project if you

- Are 18 years or older
- Have a diagnosis of Chronic Obstructive Pulmonary Disease or Chronic Heart Failure
- Are willing to commit to 8 weeks of programme attendance
- Are willing to attend a supervised exercise session, if randomly selected to do so

Unfortunately this project **will not be suitable** for you if you

- Have intellectual disability
- Are unable to provide informed consent
- Are unable to complete a self-administered questionnaire
- Have active cancer

- Have UNCONTROLLED heart, liver, kidney, diabetic or other disease which would make it unsafe for you to exercise (If these conditions are controlled by medications or other means, then you may participate.)
- Have previously attended a Chronic Disease Self-Management Programme ('Get the Most out of Life', 'Whose Health is it?' or the 'Self-Management for Wellbeing Programme')
- Have previously attended the Heart/Lung Self-Management Programme or cardiac rehabilitation programme.

Background information

At the Royal Hobart Hospital we are offering the **Self-Management for Wellbeing Programme**, a programme for people with long-term health conditions such as Chronic Obstructive Pulmonary Disease or Chronic Heart Failure. This programme is designed to help you to become an active partner with your health professionals in managing your health. **The programme itself runs over 6 weeks with one two-and-a-half hour session per week. (For this project there will also be a session for evaluation purposes before and after the programme, making it 8 weeks in total.)** The programme is lead by pairs of trained leaders. Helen and Lyn will be your leaders. It covers the topics of

- Self-Management and chronic conditions
- Making an Action Plan
- Using your mind to help manage symptoms
- Relaxation
- Dealing with anger, fear and frustration
- Exercise and fitness
- Better breathing
- Dealing with fatigue
- Healthy eating
- Enduring Guardianship and making your wishes for healthcare known
- Communication
- Medication usage
- Making treatment decisions
- Depression
- Communicating with and working with the healthcare team.

A book that has additional information about these topics is lent to you for the duration of the programme.

This is a group-based interactive programme. It involves discussion and weekly feedback to the group. You may contribute as much or as little as you wish. In addition to discussion about the above topics, each week you are asked to decide what you would like to do for the following week and to 'name up' your action plan. The following week you report back to the group how you managed with your action plan. If you had any problems, the group members may offer suggestions to help you. The leaders will assist you in finding answers to any questions.

There is no supervised exercise as part of the Self-Management for Wellbeing Programme.

Exercise is discussed during the programme and there are examples of exercises in the companion book you are lent and in information leaflets available for your use, but you do not do any exercises while attending the programme. **Therefore we would like to see if taking part in supervised exercise makes any difference to the people who attend the programme.** To do this we need to evaluate the Self-Management for Wellbeing Programme with supervised exercise and without supervised exercise. **If you agree to take part in this project, you will be randomly selected to take part in the exercise session or not. So some will attend a supervised exercise session during the same week of the programme (on a Tuesday OR Thursday from 11.00am to 12.00pm) and then everyone will attend the Self-Management for Wellbeing Programme (on a Tuesday from 1.00pm to 3.30pm.)**

So some will attend a supervised exercise session in the same week as the programme and then everyone will attend the Self-Management for Wellbeing Programme. The exercises will be decided with you and may involve using a treadmill (walking), an exercise bicycle, weights, elastic bands;

bicycle arm pedals or free exercises. You will not have to do anything you do not wish to do. Should you be using supplemental oxygen at home, it will be supplied.

Procedures

If you agree to participate in this project you will be asked to

- phase one of the project

- Complete a questionnaire and do a 6-minute walk test as part of the evaluation (week 1). This questionnaire will be anonymous.
- Attend the Self-Management for Wellbeing Programme for 6 weeks (weeks 2-7), as described above.
- Attend an exercise session before the Self-Management for Wellbeing Programme if you have been randomly selected to do this, as described above.
- Repeat the questionnaire and the 6-minute walk test (week 8) as part of the follow-up evaluation.

-phase two of the project

- We would also like to know what you think about the programme and exercise Therefore when you have completed the programme you will be asked if you would agree to being interviewed so that your opinion may be part of this project. If you agree, you will be contacted to arrange an interview time at a location of your choice. The interview will be taped and then transcribed, omitting any information which might identify you.

Transport

Should transport be a problem please let us know. Red Cross and Community Transport can often help. If you have DVA (Department of Veteran Affairs) entitlements you may be eligible for taxi fares.

Reimbursement of Costs

You will not be paid for participation in this project.

Possible Risks

- **Embarrassment:** There is a risk that you may become uncomfortable if someone discusses something which is highly personal. Suggestions for dealing with this (such as excusing yourself, perhaps to get a drink) are made at the first session.
- **Emotional Distress:** Some people may become upset when they discuss difficult issues for them such as fear of the future or communication problems with family members. Often the group support is sufficient to help in this situation. However, if further counselling were required, we will be able to suggest where you could go and would encourage you to do so.
- **Confidentiality within the group:** There is a risk that others may discuss what you say outside the group. Keeping what is said within the group is named as one of the group members' responsibilities at the first session.
- **Contributing to group discussions:** You are free to contribute as little or as much as you wish to group discussion. This is your decision and as such and is respected.
- **Privacy:** There is a potential risk to your personal privacy if any information that could identify you is recorded in the interviews when we seek your opinion. When the tapes of these interviews are transcribed, any information which might identify you will be omitted, and replaced with, for example, XXXX.

Confidentiality

- Only the investigators directly involved in the project will have access to the information collected.
- As you will be attending the hospital for this project, you will have a hospital Unit Record Number (URN). Your questionnaire will be given a code which is different to your URN, and kept separate to your URN. In this way your privacy will be protected and your questionnaires will remain anonymous.
- Once the tapes of your interviews have been transcribed, they will be erased.

- Hard copies of the data (questionnaires, transcripts of interviews) will be kept in a locked filing cabinet at the university for 7years. After this time it will be shredded. Data entered on a computer will be stored on a password-protected university computer for 7years, after which time the data will be destroyed.
- No identifying information will be stored with the data at any time.
- In any publication or presentation of this project, no information will be presented in any way that could identify you.

Participation is Voluntary

- Participation in this or any other research project is entirely voluntary. You are under no obligation to take part. If you decide to participate and then change your mind you are free to do so at any time and this will in no way affect any ongoing care you may require.
- Should you choose to withdraw, we would like to hear your reasons. As mentioned, your opinions are important to us and we would like to arrange an interview with you, to add to our research project. If you do not wish your opinions to be part of the research data, but would like to talk with us, then this will be arranged.

Withdrawal from the Project by the Investigators

Sometimes it is necessary for the investigators to withdraw someone from a project, for example, if you become unwell. At all times your best interests are our main concern and we will discuss any concerns we may have with you.

Contact Persons

Your contact person for questions relating to the Self-Management for Wellbeing Programme or the exercise session is

Helen Cameron-Tucker,
Physiotherapist,
Royal Hobart Hospital,
Liverpool Street,
Hobart,
Tasmania. 7000.
Phone: (03) 6222 8571, Tuesday 9.00am–4.00pm.
Thursday 9.00am–1.30pm.
(03)6226 4893, Monday, Wednesday, Friday 9.00am–4.00pm.
Thursday 2.00pm–4.00pm.

For any complications or adverse reactions, please contact

Dr. Richard Wood-Baker,
Department of Respiratory Medicine,
Royal Hobart Hospital,
Liverpool Street,
Hobart,
Tasmania. 7000.
Phone: (03) 6222808, ask to page Dr. Wood-Baker.

For any concerns or complaints about this project, please contact either

Dr. Helen McArdle,
Chair, Ethics Committee.
(03) 6222 8430.

Or

Mrs. Amanda McAully,
Executive Officer, Ethics Committee.
(03) 6226 2763.

Ethical Guidelines

This project has received ethical approval from the Southern Tasmania Health and Medical Human Research Ethics Committee. It has also been approved by the Research Advisory Committee, Royal Hobart Hospital and the Clinical Support Services, Royal Hobart Hospital.

It will be conducted according to the 'National Statement on Ethical Conduct in Research Involving Humans (June, 1999). This statement has been developed by the National Health and Medical Research Council of Australia, to protect the interests of anyone agreeing to participate in research involving humans.

Results of the Investigation

The results of this project will be published in relevant peer-reviewed journals and on websites, and presented at conferences and seminars. A copy of the PhD thesis will be available in the University of Tasmania Clinical School Library and Department of Education Library for your perusal if you wish. The results of your 6-minute walk tests will be made available to you. This information may also be made available to your doctors or other health professionals if you wish.

Information Sheet and Consent Form

You will be provided with a copy of this Participant Information and Consent Form for your records.

Thank-you for taking the time to read this information.

A.3 Chronic Disease Self-Management Programme Brochure

<p>What is the 'Self Management for Wellbeing' programme?</p> <p>The Royal Hobart Hospital, Tasmania offers the 'Self Management for Wellbeing' programme. This is an interactive programme and does not include supervised exercise.</p> <p>The programme is conducted in a series of group sessions run over 6 weeks.</p> <p>Programme commences on:-</p> <p>Time:- _____</p> <p>Venue:- 2D Physiotherapy Gym.</p> <p>The sessions are led by trained programme leaders.</p> <p>* Please remember to bring your reading glasses.</p>	<p>What is the aim of the 'Self Management for Wellbeing' programme?</p> <p>The 'Self Management for Wellbeing' programme aims to:</p> <ul style="list-style-type: none"> • promote confidence, skills, and ability to manage health through problem solving, sharing experiences, education, goal setting and action planning. • encourage the adoption of healthy behaviours such as a self-managed regular exercise/physical activity routine, healthy eating and relaxation. • promote an understanding of living with long-term health conditions. • assist people living with long-term health conditions to maximise their living skills and get the most out of life. <p>Commitment to attend all sessions means you will get the most out of the programme.</p> <p>Carers/partners are invited to attend the educational programme.</p>	<p>Programme</p> <p>Data Collection—pre-programme</p> <p>Overview/Goal setting/Action Planning (every session). Relaxation/Symptom Management</p> <p>Feedback/Problem Solving (rest of sessions) Emotions/Fitness/Exercise</p> <p>Fitness/Exercise/Better Breathing/Fatigue</p> <p>Healthy Eating/Enduring Guardianship/Communication</p> <p>Medication Use/Making Treatment Decisions/Depression</p> <p>Informing the Health Care Team/Working with Health Care Professionals/Future Plans</p> <p>Data Collection—post-programme</p>
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A.4 Eligibility Assessment Form

CDSMP STUDY SCREENING ASSESSMENT

Primary Diagnosis When diagnosed
Co-morbidities

Precautions

Referral From (name), Private Specialist/ GP/ ward/ OP Clinic / DEM

G.P. Ph: Specialist Ph:

Address Address

Inclusion Criteria

Adult over 18 year Y/N

Willing to attend a supervised exercise programme Y/N

Willing to commit to 8 weeks of programme attendance Y/N

Diagnosis of COPD based on spirometry: FEV1 = FEV1/FVC =

MRC dyspnoea scale 1 2 3 4 5

Diagnosis of left systolic CHF based on echocardiography NYHA scale 1 2 3 4

LVEF =

Exclusion Criteria

Intellectual disability Y/N

Unable to provide informed consent Y/N

Unable to complete a self-administered questionnaire Y/N

Resting HR > 120bpm RHR = Y /N

Resting SBP > 180mmHg and/or resting DBP > 110mmHg SBP/DBP = Y/N

Unstable angina Y/N Severe cardiac valve disease Y/N

Uncontrolled atrial or ventricular arrhythmias Y/N Uncompensated CHF Y/N

Active pericarditis or myocarditis Y/N Acute systemic illness or fever Y/N

Recent embolism Y/N Thrombophlebitis Y/N

Uncontrolled diabetes Y/N Severe orthopaedic problems Y/N

Active retinal haemorrhage Y/N Retinopathy Y/N

Metabolic disorders (acute thyroiditis, recent CVA, uncontrolled liver disease or renal disease, active cancer, other.....) Y/N

Previous attendance at cardiopulmonary rehab or SMWB programme Y/N

Verbal agreement to join study? Y /N

If invitation to join the study is **declined**, state reason (if any).

SUBJECTIVE ASSESSMENT Primary Diagnosis/date diagnosed

GP Specialist Precautions

Present Medical History

Past Medical History

- respiratory

- cardiac

- hypertension Y /N / medication controlled PVD: Y/N

- angina Y/N last episode: If recent, frequency (per week etc):

Pain/tightness/SOB Duration Pain (0–10):

Referred pain distribution

- oedema Y/N

- orthopnoea Y/N number of pillows:

- diabetic Type 1/Type 2/NIL GORD: Y /N

- orthopaedic

- neurological

- other

Medications

Social History

Employment History

Smoking History

Alcohol Intake

Cough Y/N When:

Wheeze Y/N When:

Mucus Y/N When:

volume: grade: (now)

volume: grade: (usually)

S.O.B. - at rest Y/N mild/mod/severe. Triggers to S.O.B:

MRC Dyspnoea Scale 1 2 3 4 5

NYHA Scale 1 2 3 4

ADL:

Driving Y/N comment

Continence

COPD Specific Questions

Last time use of puffers checked?

Who would you go to, to have puffer use checked?

Immunisations up to date? Influenza Y/N Pneumococcal Y/N

CHF Specific Questions

Daily weighing? Y/N

Fluid restriction ($\leq 1.5\text{L/day}$) Y/N

Salt restriction ($\leq 1 \text{ tspn} = 2000\text{mg/day}$) Y/N

OBJECTIVE ASSESSMENT

Appearance - chest shape - other

- shoulders elevated at rest Y/N on exertion Y/N

- accessory muscles active at rest Y/N on exertion Y/N

Breathing Pattern / Breathing Control

- at rest

- on exertion

Breathing Control - instruction given: Y/Not required

- comment

Inhaler Technique - puffer/turbuhaler/accuhaler/handihaler/spacer device

- correct/incorrect

- instruction given: Y/Not required

Use of angina medication – GTN/anginine tablets correct/incorrect

Cough

FET - instruction : Y/Not required

Auscultation

VFT/CXR/Other

Spinal Mobility – Cervical - Thoracic

Height Weight BMI

6-Minute Walk – distance stops RPE SOB

Resting(pre) SaO₂/HR Resting(pre) BP post SaO₂/HR post BP

PLAN

Helen Cameron-Tucker

Department of Physiotherapy, RHH. 2004

Signature and Date

A.5 Consent Form

INFORMED CONSENT FORM

‘A comparison of the Self-Management for Wellbeing Programme plus supervised exercise with the Self-Management for Wellbeing Programme alone for people with Chronic Obstructive Pulmonary Disease or Chronic Heart Failure’.

By signing and dating this Informed Consent Form, I indicate that

1. I have read and understood the ‘Participant Information’ for this project.
2. The nature and any possible effects of the project have been explained to me.
3. I understand that the project involves 2 phases:
 - completing questionnaires and doing a 6-minute walk test before and after the Self Management for Wellbeing Programme. I may be allocated to a supervised exercise session as well as the Programme, or I may be allocated to the Programme alone.
 - taking part in a voluntary interview, if I choose to, after the completion of the programme. The times that these will be administered has been explained to me.
4. I understand that I may contribute as little or as much as I choose to do so to the group. Anything I say will remain within the group. At all times my personal privacy will be respected and protected.
5. I have been informed that the results of the project may not be of any direct benefit to my medical management.
6. I have had the opportunity to ask any questions about the project and the evaluation. Any questions have been answered to my satisfaction.
7. I agree that the research data gathered for this project may be published or presented and that I will in no way be identified.
8. I agree to participate in this investigation and I understand that I may withdraw at any time, and this will not affect my medical care or my relationship with my healthcare professionals.

Please print your name.....

Your Signature.....

Today's Date...../...../.....

Name of Witness.....

Address.....

Date...../...../.....

Signature.....

STATEMENT BY THE RESEARCHER

I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of researcher.....

Signature of researcher.....Date...../...../.....

A.6 Questionnaire: Cover Sheets and Demographic Information

SELF-MANAGEMENT FOR WELLBEING STUDY

Pre Programme Evaluation

Thank-you for agreeing to participant in this study.

The following pages contain questions that we would like you to answer.

The page headed 'Your Personal Information' will be detached, so that your responses to the questionnaires will remain anonymous.

Please answer each question. There are no right or wrong answers. It is YOUR response which is important.

**THANK-YOU FOR TAKING THE TIME TO
ASSIST US WITH THIS STUDY**

YOUR PERSONAL INFORMATION
Pre Programme

Your Name:URN:ID:.....

Your Address:.....Postcode:

Your GP

GP's address:

Date of questionnaire completion:..... Pre or post programme

Gender (please circle): M/F **Age (as at last birthday, in years):**

Nationality (please tick one box): Marital Status (please tick one box)

Australian	
Australian Aborigine	
Australian South Sea Islander	
Torres Strait Islander	
Other	

Never married	
Widowed	
Divorced	
Separated	
Married	

Highest level of schooling (please tick one box)

Did not go to school	
Overseas Visitor	
Still at school	
Year 8 or below	
Year 9 or equivalent	
Year 10 or equivalent	
Year 11 or equivalent	
Year 12 or equivalent	

Chronic condition (please tick which chronic condition(s) you have and the number of years you have had the condition)

Years

Emphysema or COPD		
Heart failure		
Other condition(s)		

Please turn the page.

SELF-MANAGEMENT FOR WELLBEING STUDY**Post Programme Evaluation**

Thank-you for having attended the Self-Management for Wellbeing Programme and for agreeing to participant in this study.

The following pages contain questions which we would like you to answer.

The page headed 'Your Personal Information' will be detached, so that your responses to the questionnaires will remain anonymous.

Please answer each question. There are no right or wrong answers. It is YOUR response which is important.

**THANK-YOU FOR TAKING THE TIME TO
ASSIST US WITH THIS STUDY**

**YOUR PERSONAL INFORMATION
Post Programme**

Your Name:URN:ID:.....

Your Address:.....Postcode:

Your GP

GP's address:

Date of questionnaire completion:.....Post programme

Please turn the page.

A.6.1 CHAMPS Activities Questionnaire for Older Adults

The CHAMPS Activities Questionnaire for Older Adults is presented on the following pages.

CHAMPS Activities Questionnaire for Older Adults

CHAMPS: Community Healthy Activities Model Program for Seniors
Institute for Health & Aging, Center for Healthy and Active Aging
University of California San Francisco
Stanford Center for Research in Disease Prevention, Stanford University
(11/06/00) © Copyright 1998

DATE.....

ID.....

PRE..... POST.....

This questionnaire is about activities that you may have done in the past 4 weeks. The questions on the following pages are similar to the example shown below.

INSTRUCTIONS

If you **DID** the activity in the past 4 weeks:

Step #1 Check the YES box.

Step #2 Think about how many TIMES a week you usually did it, and write your response in the space provided.

Step #3 Circle how many **TOTAL HOURS in a typical week** you did the activity.

Here is an example of how Mrs. Jones would answer question #1: Mrs. Jones usually visits her friends Maria and Olga twice a week. She usually spends one hour on Monday with Maria and two hours on Wednesday with Olga. Therefore, the total hours a week that she visits with friends is 3 hours a week.

In a typical week during the past 4 weeks, did you...						
1. Visit with friends or family (other than those you live with)? <input type="checkbox"/> YES How many TIMES a week? <u>2</u> → <input checked="" type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	<u>3-4½</u> hours	5-6½ hours	7-8½ hours 9 or more hours

If you **DID NOT** do the activity:

- Check the NO box and move to the next question

In a typical week during the past 4 weeks, did you ...							
1. Visit with friends or family (other than those you live with)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
2. Go to the senior center? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
3. Do volunteer work? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
4. Attend church or take part in church activities? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
5. Attend other club or group meetings? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
6. Use a computer? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
7. Dance (such as square, folk, line, ballroom) (do <u>not</u> count aerobic dance here)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
8. Do woodworking, needlework, drawing, or other arts or crafts? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
9. Play golf, carrying or pulling your equipment (count <u>walking time</u> only)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
10. Play golf, riding a cart (count <u>walking time</u> only)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
11. Attend a concert, movie, lecture, or sport event? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
12. Play cards, bingo, or board games with other people? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
13. Shoot pool or billiards? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
14. Play singles tennis (do <u>not</u> count doubles)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
15. Play doubles tennis (do <u>not</u> count singles)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
16. Skate (ice, roller, in-line)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
17. Play a musical instrument? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
18. Read? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
19. Do heavy work around the house (such as washing windows, cleaning gutters)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
20. Do light work around the house (such as sweeping or vacuuming)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
21. Do heavy gardening (such as spading, raking)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
22. Do light gardening (such as watering plants)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
23. Work on your car, truck, lawn mower, or other machinery? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
**Please note: For the following questions about running and walking, include use of a treadmill.							
24. Jog or run? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
25. Walk uphill or hike uphill (count only uphill part)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
26. Walk <u>fast or briskly</u> for exercise (do <u>not</u> count walking leisurely or uphill)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
27. Walk <u>to do errands</u> (such as to/from a store or to take children to school <u>count walk time only</u>)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
28. Walk <u>leisurely</u> for exercise or pleasure? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
29. Ride a bicycle or stationary cycle? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
30. Do other aerobic machines such as rowing, or step machines (do <u>not</u> count treadmill or stationary cycle)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
31. Do water exercises (do <u>not</u> count other swimming)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
32. Swim moderately or fast? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
33. Swim gently? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
34. Do stretching or flexibility exercises (do <u>not</u> count yoga or Tai-chi)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
35. Do yoga or Tai-chi? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
36. Do aerobics or aerobic dancing? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
37. Do moderate to heavy strength training (such as hand-held weights of <u>more than 5 lbs./2.3kgs</u> , weight machines, or push-ups)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you ...							
38. Do light strength training (such as hand-held weights of <u>5 lbs./2.3kgs or less</u> or elastic bands)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
39. Do general conditioning exercises, such as light calisthenics or chair exercises (do <u>not</u> count strength training)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
40. Play basketball, soccer, or racquetball (do <u>not</u> count time on sidelines)? <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
41. Do other types of physical activity not previously mentioned (please specify)? _____ <input type="checkbox"/> YES How many TIMES a week? _____ → <input type="checkbox"/> NO	How many TOTAL <u>hours a week</u> did you usually do it? →	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

Thank You

A.6.2 Stages of Change – Short Form Questionnaire and Exercise Criteria

DATE.....

ID NUMBER.....

PRE.....POST.....

YOUR REGULAR EXERCISE

We would like to know about your regular exercise.
Please read and answer the following question.

Regular Exercise is any **planned** physical activity (e.g., brisk walking, aerobics, bicycling, swimming, line-dancing, tennis, doing formal exercises etc.) performed to increase or maintain health and physical fitness. Such exercise should be performed on **all or at least 5 days** of the week to accumulate **30 minutes or more** per day. Exercise does not have to be painful to be effective but should be done at a moderate level that increases your breathing rate and makes you feel warmer.

- Do you exercise regularly according to the definition above?Y/N (*please circle*)
- Mark the **ONE** statement that applies to **YOU**.

_____ Yes, I have been exercising regularly for more than 6 months.

_____ Yes, I have been exercising regularly, but for less than 6 months.

_____ No, but I intend to exercise regularly in the next 30 days.

_____ No, but I intend to exercise regularly in the next 6 months.

_____ No, and I do not intend to exercise regularly in the next 6 months.

A.6.3 Exercise: Self-Efficacy Measure

Date....../.../....

ID Number.....

YOUR CONFIDENCE TO EXERCISE

We would like to know how confident you are that you will do your regular exercise when other things get in the way. Read the following items and enter in the box the number that best expresses how each item relates to you when you exercise. Please answer using the following 5-point scale:

- 1 = Not at all confident 4 = Very confident
 2 = Somewhat confident 5 = Completely confident
 3 = Moderately confident

Using the scale 1 to 5, circle ONE only for each statement below.

	Not at all confident		Completely confident	
My confidence to exercise when.....				
I am under a lot of stress is.....1	2	3	4	5
I am depressed is.....1	2	3	4	5
I am anxious is.....1	2	3	4	5

My degree of confidence to exercise when.....

I don't feel I have the time is.....1	2	3	4	5
I don't feel like it is.....1	2	3	4	5
I am busy is.....1	2	3	4	5

My degree of confidence to exercise when.....

I am alone is.....1	2	3	4	5
I have to exercise alone is.....1	2	3	4	5
my exercise partner decides not to exercise that day is....1	2	3	4	5

We would like to know how confident you are that you will do your regular exercise when other things get in the way. Read the following items and enter in the box the number that best expresses how each item relates to you when you exercise. Please answer using the following 5-point scale:

- 1 = Not at all confident 4 = Very confident
 2 = Somewhat confident 5 = Completely confident
 3 = Moderately confident

Using the scale 1 to 5, circle ONE only for each statement below.

	Not at all confident			Completely confident	
My degree of confidence to exercise when.....					
I don't have access to exercise equipment is.....	1	2	3	4	5
I am travelling is.....	1	2	3	4	5
my gym is closed is.....	1	2	3	4	5
My degree of confidence to exercise when.....					
my friends don't want me to exercise is.....	1	2	3	4	5
my significant other does not want me to exercise is.....	1	2	3	4	5
I am spending time with friends or family who do not exercise is.....	1	2	3	4	5
My degree of confidence to exercise when.....					
it's raining or snowing outside is.....	1	2	3	4	5
it's cold / too hot outside is.....	1	2	3	4	5
the roads or footpaths are wet is.....	1	2	3	4	5

A.6.4 Shortness of Breath Visual Analogue Scale

DATE..... ID NUMBER.....
PRE.....POST.....

SHORTNESS OF BREATH

We would like to know about your shortness of breath or breathlessness.

1. Please indicate how **severe** your shortness of breath or breathlessness has been on average over the **last 4 WEEKS**, by putting a *vertical* (straight up and down) mark on the line below.

No Shortness of Breath	Severe Shortness of Breath
------------------------	----------------------------

2. Please indicate how **frequently** you have experienced shortness of breath or breathlessness over the **last 4 WEEKS**, by putting a *vertical* (straight up and down) mark on the line below.

None of the time	All of the time
------------------	-----------------

A.6.5 Short- Form 36 Questionnaire Version 2 (SF-36v2)

The SF-36v2 questionnaire is presented on the following pages.

DATE.....

ID NUMBER.....

PRE.....POST.....

Your Health and Well-Being

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼ <input type="checkbox"/> 1	▼ <input type="checkbox"/> 2	▼ <input type="checkbox"/> 3	▼ <input type="checkbox"/> 4	▼ <input type="checkbox"/> 5

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼ <input type="checkbox"/> 1	▼ <input type="checkbox"/> 2	▼ <input type="checkbox"/> 3	▼ <input type="checkbox"/> 4	▼ <input type="checkbox"/> 5

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

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c Lifting or carrying groceries.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d Climbing <u>several</u> flights of stairs.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
e Climbing <u>one</u> flight of stairs.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
f Bending, kneeling, or stooping.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
g Walking <u>more than a kilometre</u>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
h Walking <u>several hundred metres</u>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
i Walking <u>one hundred metres</u>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
j Bathing or dressing yourself.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

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

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b <u>Accomplished less</u> than you would like	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
--------------------	---------------------	---------------------	-------------------------	---------------------

- a Cut down on the amount of time you spent on work or other activities

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

- b Accomplished less than you would like

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

- c Did work or other activities less carefully than usual

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
------------	----------	------------	-------------	-----------

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Have you been very nervous?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Have you felt calm and peaceful?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e Did you have a lot of energy?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f Have you felt downhearted and depressed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g Did you feel worn out?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h Have you been happy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i Did you feel tired?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

11. How TRUE or FALSE is each of the following statements for you?

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
▼	▼	▼	▼	▼

- a I seem to get sick a little
easier than other people..... ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- b I am as healthy as
anybody I know..... ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- c I expect my health to
get worse ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- d My health is excellent ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Thank you for completing these questions!

A.6.6 Partners in Health Scale

DATE..... ID.....

PRE.....POST.....

PARTNERS IN HEALTH SCALE

Please circle the number that most closely fits for you

1 Overall, what I know about my health condition(s) is:

0	1	2	3	4	5	6	7	8
Very little			Something			A lot		

2 Overall, what I know about the treatment of my health condition(s) is:

0	1	2	3	4	5	6	7	8
Very little			Something			A lot		

3 I take the medications(s) prescribed by my doctor:

0	1	2	3	4	5	6	7	8
Never			Sometimes			Always		

4 I participate with my health care providers in making decisions about my health condition(s) :

0	1	2	3	4	5	6	7	8
Very little			Sometimes			A lot		

5 I arrange appointments as recommended by my health care providers:

0	1	2	3	4	5	6	7	8
Never			Sometimes			Always		

6 I attend appointments as recommended by my health care providers:

0	1	2	3	4	5	6	7	8
Never			Sometimes			Always		

- 7 I understand why I need to check and write down information about my health conditions e.g., blood sugar, blood pressure, peak flow, weight and symptom(s) such as shortness of breath and pain

0	1	2	3	4	5	6	7	8
Very little			Fairly well			A lot		

- 8 I check and write down information about my self-testing results, e.g. blood sugars, blood pressure, peak flow, weight and symptom(s) such as shortness of breath and pain

0	1	2	3	4	5	6	7	8
Never			Sometimes			Always		

- 9 I understand what to do when my symptom(s) get worse:

0	1	2	3	4	5	6	7	8
Very little			Fairly well			A lot		

- 10 I take the right actions when my symptom(s) get worse:

0	1	2	3	4	5	6	7	8
Never			Sometimes			Always		

- 11 I am able to manage the effect of my health condition(s) on my physical activity (e.g. walking, household tasks):

0	1	2	3	4	5	6	7	8
Not very well			Fairly well			Very well		

- 12 I am able to manage the effect of my health condition(s) on how I feel (i.e. my emotions and social life):

0	1	2	3	4	5	6	7	8
Not very well			Fairly well			Very well		

- 13 I am able to manage the effect of my health condition(s) on how I get along with other people (i.e. on my social life):

0	1	2	3	4	5	6	7	8
Not very well			Fairly well			Very well		

- 14 Overall, I manage to live a healthy life (e.g., no smoking, moderate alcohol, diet, exercise etc.):

0	1	2	3	4	5	6	7	8
Not very well			Fairly well			Very well		

A.7 Objective Data Record Sheet

CDSMP STUDY OBJECTIVE DATA RECORD SHEET

ID. NUMBER.....

6-MINUTE WALK TEST

	Resting SaO ₂ /HR	Resting B.P.	Finish SaO ₂ /H R	Finish B.P.	DIST.	STOPS	S.O.B.	R.P.E.
Pre CDSM								
Post CDSM								

BODY MASS INDEX (BMI)

	Height (m)	Weight (Kg)	BMI
Pre			
Post			

Date	FEV1 L%	FEV1/FVC %	MRC	LVEF %	NYHA	Referral Source Private Specialist/GP/ ward/OPD Clinic/ DEM/database

Previous Attendance at Rehabilitation Programme....CCPRP / SMWB / Nyears ago

Randomised to Supervised Exercise.....Y/N

Exercise Sessions Attended..... 1 2 3 4 5 6 N/A

CDSMP Sessions attended (circle).....Did Not Start

.....Pre Data.....Post Data

.....1 2 3 4 5 6

Post-programme Supervised Exercise.....Continue / Commence / N

Staff use: entered on database Y

A.8 Supervised Exercise Record Sheet

EXERCISE REPORT								
Date								
Resting SaO ₂ /HR								
BP								
Recovery at ...mins								
SaO ₂ /HR								
B.P.								
Weight								
TREADMILL								
Date	Time	Slope	Speed	SaO ₂ /HR	BP	RPE	SOB	COMMENT
BICYCLE								
Date	Time	Speed	SaO ₂ /HR	BP	RPE	SOB	COMMENT	

Helen Cameron-Tucker
 Department of Physiotherapy, Royal Hobart Hospital. 1997
 Reviewed 1998 – 2004

Date										
Arm Pedals										
Step Ups										
Wall Push-ups										
Half Squats										
Theraband-(colour)										
- arms										
- legs										
Step Downs - R										
- L										
Mini Tramp										
Fit Ball										
Pulleys - (R) out										
- (L) across										
Pulleys - (L) out										
- (R) across										
Weights - biceps (R)										
- biceps (L)										
- triceps (R)										
- triceps (L)										
- deltoid (R)										
- deltoid (L)										

Aim to increase intensity (work time or repetitions) first, then increase weight or resistance.
Aim to decrease rest time as able.

STOP exercise if you experience chest pain, jaw, neck or arm pain, unusual breathlessness, dizziness, faintness or nausea, coldness or clamminess, ankle swelling, coughing up blood.

AN EXERCISE OR PHYSICAL ACTIVITY SESSION MUST INCLUDE:
WARM UP: 5 to 10 minutes of light exercise, stretches, walking
CONDITIONING: 5 to 7 times per week
COOL DOWN: 5 to 10 minutes of light walking, exercise, stretches

Signature

A.9 Prompts during the Interviews

Examples of Questions to be used in the Qualitative Research

Completers

Tell me about living with your condition.

What does health mean to you?

How would you describe a chronic condition?

What does having a chronic condition mean for you?....How do you 'live' with it?

What effect has it had on how you think about yourself?

What effect has it had on how you think about your life?

Tell me about exercise.

What do you think about exercise?

What did you think about coming to the gym/not coming to the gym for supervised exercise?

How has your exercise regime changed since doing the programme?

How did coming to the gym / not coming to the gym for supervised exercise contribute to this?

What do you think about including coming to the gym/not coming to the gym for supervised exercise as part of the programme?

Tell me why you came along to the programme.

Why did you decide to come along to the Self-Management for Wellbeing Programme?

What kept you coming to the programme?

Tell me what you thought about the programme.

From your perspective, what has the programme been like?

What did you like about the programme?

What did you dislike about the programme?

What have you remembered?

How has this changed the way you do things?

How has this changed the way you think about your condition/yourself/your life?

From what you have remembered, what has been the most important thing (s) for you?

How has the programme helped you to manage your condition?

What does self-management mean to you?

What suggestions do you have for the programme?

Tell me your 'take home message'

If you could sum up in a few words what your 'take home message'the most important partabout the programme has been for you, what would those words be?

Similarly, what is your 'take home' message about coming to the gym / not coming to the gym for supervised exercise?

What would your recommendation about the programme with / without gym attendance for others be?

Tell me any other comments you may have.

Examples of Questions to be used in the Qualitative Research

Withdrawals

Tell me about living with your condition.

What does health mean to you?

How would you describe a chronic condition?

What does having a chronic condition mean for you?....How do you 'live' with it?

What effect has it had on how you think about yourself?

What effect has it had on how you think about your life?

Tell me about exercise.

What do you think about exercise?

What did you think about coming to the gym/not coming to the gym for supervised exercise?

How has your exercise regime changed since doing the programme?

How did coming to the gym / not coming to the gym for supervised exercise contribute to this?

What do you think about coming to the gym/not coming to the gym for supervised exercise as part of the programme?

Tell me why you came along to the programme.

Why did you decide to come along to the Self-Management for Wellbeing Programme?

What stopped you from coming to the programme?

How could we have helped to make it easier for you to keep coming?

Tell me what you thought about the sessions you attended.

From your perspective, what were the programme sessions you came to like?

What did you like about those sessions?

What did you dislike about those sessions?

What have you remembered from those sessions?

How has this changed the way you do things?

How has this changed the way you think about your condition/yourself/your life?

From what you have remembered, what has been the most important thing (s) for you?

How has the programme helped you to manage your condition?

What does self-management mean to you?

What suggestions do you have for the programme?

Tell me your 'take home message'

If you could sum up in a few words what your 'take home message'the most important part ...about the sessions you attended or the programme in general has been for you, what would those words be? Similarly, what is your 'take home' message about coming to the gym/not coming to the gym for supervised exercise?

What would your recommendation about the programme with/without gym attendance for others be?

Tell me any other comments you may have.

A.10 Thank-you Letter

Department of Physiotherapy,
Royal Hobart Hospital,
Liverpool Street,
Hobart,
Tasmania. 7000

....., 2008.

Dear.....,

This letter is to thank you so much for participating in my study during 2005–2007 of the effect of supervised exercise with the Chronic Disease Self-Management Programme (known as the Self-Management for Wellbeing Programme in the Royal Hobart Hospital). My PhD thesis has been submitted for examination. Without your willing participation my study would not have been possible.

I found that attending one hour of supervised exercise per week did not make any difference to the distance you walked in the 6-minute walk test. With or without supervised exercise, all of you participating in the study showed a small statistically significant increase in the distance you walked in the 6-minute walk test. However, those of you who attended the supervised exercise sessions tended to exercise more frequently, for longer duration, had less breathlessness and had improved quality of life for physical activity compared with those who did not have supervised exercise. We will need to study this further to see if the benefit suggested by my research is what we call statistically significant.

I also wish to say thank-you to those who took part in the interviews with me. What stood out for me were the ways you have learnt to manage the effect of COPD on your lives; your sense of commitment to the study, even when the programme did not meet all of your needs; your understanding of 'self-management' expressed in terms of 'self-reliance, self-awareness, and acceptance'; and your expressed wish that you be offered choices for your healthcare and that your preferences be respected. Your comments add much to our clinical work. You all thought exercise is important and that it should be offered as an option with the Self-Management for Wellbeing Programme. We are now doing that.

Once again, I thank you all so much for agreeing to take part in my study. You have added to what we know about these programmes, and you are helping us to offer the best programme we can.

Yours sincerely,

Helen Cameron-Tucker,

Physiotherapist.

Appendix B: Data

B.1 Initial Coding

B.2 Example of Coding from Transcripts

B.3 Example of Memos

B.4 Raw Quantitative Data

B.5 Outcomes: Study Participants versus Balance of Referrals

B.1 Initial Coding

Table 36: Relationship of Initial Coding to Themes and Categories

Categories	Emerging Themes	Re- Coding	Initial Coding
Living with COPD	Meaning of COPD	Losses: - physical capacity and emotional harmony - expectations - roles - independence - stigma	Difficult emotions - reason for difficult emotions - managing difficult emotions Effect on life now: - changed life - limited activities - pacing activities - rely on help
	Self-developed strategies	Planning and pacing Acceptance of limitations	
A Personal Meaning of Self-management	Self-management activities	Follow medication regime Exercise and have a healthy diet Maintain a sense of independence	Self-management -meaning -‘Take home’ message
	Self-referent Concepts	Self-awareness and acceptance Self reliance	
A Shared Engagement	Presenting and Participating	CDSMP - motivation for commencing and continuing the programme	CDSMP -reason for attendance - positives - negatives - role models -social comparison - identification - action plans
	Group benefits	- social processes	
	A Self-Focus	Self- consideration Self-efficacy, self-regulation	Diagnosis Hope Smoking
	A Personal Engagement	Participant engagement -supervised exercise -CDSMP	Programme Comparisons -positive -negative

B.2 Example of Initial Coding from Transcripts

It's myself that I've got to tell myself to do, and it's not too easy. [self-referent thoughts]

That is an interesting comment "telling myself to do it". Did the programme help you at all? Can you tell me how the programme helped you in that regard?

It made me realise that yourself is the person concerned. It's okay to be concerned about other people and their health, but it is your own ability and mentally I felt a lot better because it did things for me that motivated me more. [self-referent thoughts, programme positive]

What sorts of things did it motivate you to do?

Walking for a start, remember when we first started, we had to put down what we were going to try and do, well that did, and I started to walk down the lane and walk back, a couple of times a day, but then I stopped. [action plans, motivational level, barriers]

What got in the way, what stopped you?

Me, mentally, I just got lazy, but I'm one of these blokes, even at football practice they had to drive me. [self-referent thoughts]

What sorts of things do you need to keep you on the go, to keep driving you to do it?

Well, I think I need an appointment to be somewhere, and I know when I get there that I have to do something, because I am obligated because I have committed myself, and that is what you have to do, if I never said to you that I would do something, invariably I wouldn't do it. I am just lazy. I'd rather go and have a packet of chips than go for a walk down the lane. Or have a coffee and some cake, anything. [self-referent thoughts, motivation]

And do you? Do you have the coffee and cake instead of going for a walk?

Yes. I just potter around here but that's not really walking, it's not a power walk or anything like that, and down to the end of the lane and back to here is as much as I can do.

So has the programme changed the way you do things?

It has given me a better outlook, a broader outlook. [programme positive] But it never changed me as far as exercise went, which is what I thought, as I said to Ailsa I thought I was going to get a little bit more out of it on the exercise side of it, [programme negative] which is probably my fault for not

following it through, if I'd followed it through I might have been better. I might have got more out of it than what I did. [self-referent thoughts]

So that would have come back to making the commitment to yourself wouldn't it?

That's right, and it might even have been an ongoing thing.

How could we have made that easier?

Well if I had said to you when I first went there that I wanted to do exercise it might have helped you to help me. [stating goal/plan]

Okay, so a few weeks down the track we can certainly look at that, no problem at all.

That's good.

The programme was called the "Self Management for Well Being Programme" so we often wonder what self management actually means to the people who come along. Have you ever actually thought of that, what it means to you?

Yes, it means exactly what I have just been talking about, committing yourself to exercise and all the other items that came out of the 8 weeks, if you have picked up on each individual thing and then followed them through, you would be better off. [self-management definition]

What sorts of things Chas, what are the things that stand out for you? Exercise is clearly important to you, you have mentioned that a number of times.

I think being positive, and thinking positive thoughts is the way to go, I think you, don't let yourself get down in the dumps, lift yourself above that and I think you are better off if you think constructively and not destructively. I can't see that I got anymore than that out of it, but generally as it went along, you picked up little things that reinforce that. [programme positive]

And where did those little things mostly come from.

What people said about, I don't know whether it was Larry or Barry, he did it when he wanted to do it, and then he'd go and sit down, and that to me was the same thing as I was going through [identification], but he was much more sicker than I was lung wise, so I should have been able to do more than what he was saying [social comparison], but I never because I was too lazy and that's not

good, but I know I am but what can you do, if someone can show me how to get out of lethargic thinking. [self-referent thoughts]

Did you find then that those weeks when you made a commitment to yourself to do something you reported back to the group, what was the impact of that on helping you to commit?

Not too bad, but I don't think I did enough, I think I could have done more. [self-referent thoughts]

What about your eating, you named cutting out snacks?

Yes we did, we cut out sugar altogether. [action plan]

Has that continued?

Yes, we are still doing that, but I am still, I don't know whether I'm trying to compensate for the sugar or what.

So did you lose anymore weight?

Yes, I am down to 16 stone, I was 17. [goal/action plan]

Well done, so you have lost six kilos doing the programme, 6.4 to be precise is a stone. That is fantastic.

B.3 Example of Memos

GARY (intervention/pleased)

difficult emotion: anger, frustration, annoyance, worry, depression, remorse

reason for difficult emotion: limited activities

managing difficult emotion: external resources

-customers, transplant giving hope, education of self

-social comparison-down

effect of programme: awareness of breaking into vicious cycle = moving towards internal resource in managing difficult emotions.

self concept: mortal, philosophical, strong willed, physical self concept ill defined... he presents himself in a positive light (cf. Brown, 1997,....people perceive themselves positively)

previous self concept: athlete/ physically active

preferred self concept: as previously

self esteem: acceptance, fear of failure, guilt

physical 'identity level':

- constantly offers reasons (it hurts, never one to do it, can't take the pain) why he does not become more physically active, even though this is his preferred identity; (para 103) high expectation offered as an intransient personality trait, incapable of modifying (cf. Chris)

-voices fear of failure (and hence undermining of his self efficacy). paragraph 111 lists steps/contingencies in case he does not meet his goals.

-His comment re working for as long as he could and stopping work, 'kicking and screaming', indicates he was trying to retain his independence. His condition dictated otherwise and he began to engage in pre-emptive excuse making (cf. Charmaz's 'contingent self').

-effect of programme: appears to have lowered self esteem (paragraph 171, 'terrible') following emphasis on setting targets and action plans.

supervised exercise

-advantage: motivation, identification with others, social, an outing, physical activity attained by just getting there

- disadvantage: none

- recommend supervised exercise: did not link the two
- general advantage of exercise: necessary for health

exercise motivation: appears mainly extrinsic:

- supervised exercise (para 119, 123),
- prospect of transplantation offers him hope and extrinsic motivation.
- he appears to have some intrinsic motivation (self paragraph 111,)
- his biggest barrier is fear of failure.

Summary

- pre-emptive excuse making
- strong emotional impact due to declining activities due to condition (SOB)
- programme positive: beginnings of emotional management (vicious cycle)
- beginnings of internal motivation to maintain fitness

MICHAEL (control/pleased)

difficult emotion: frustration, laziness, boredom, irritability

reason for difficult emotion: limited activities due to SOB

managing difficult emotion: internal resources

- acceptance by self and others (Charmaz, 1999, p 372)
- exercise
- positive self talk (paragraph 53-59)
- re-evaluation of assumptions e.g. 'sissy' jobs, reconciles with self concept of being masculine / 'masculine' roles

self concept: invincibility, physically active, perseveres, masculine, team worker (maintains sense of independence)

previous self concept: phys active, independent

preferred self concept: physically active, self-reliant, self-sufficient (positive of programme)

self esteem: preserves self esteem by noting 'no difference' since smoking cessation, previously 'lazy'

physical 'identity level':

- he knows he wants to be physically active again, and he acknowledges changes /adjustments he has made (paragraph 35, 39, 43)

-affirmations of others re his condition have helped

-altered life trajectory but philosophical (paragraph 53-59)

-effect of programme: has helped him to identify a preferred self (paragraph 203-205)

supervised exercise

- advantage: social comparison re intensity, duration; alternate venue would give variety

- disadvantage: none

- recommend sup ex: YES for benefits as above

-general advantage of exercise: delay disease progression, maintenance, positive impact on mood, mange co-existing conditions

exercise motivation: appears mainly intrinsic

-lung transplant prospect provides extrinsic motivation, but his motivation to exercise appears mainly intrinsic

- would have liked gym attendance for social comparison

-recognises benefit of supervised exercise as source of external motivation for others if they are not intrinsically motivated

Summary

- internal resources (positive self talk, acceptance) for emotional management and exercise

-programme positive: self reliance, reinforced by identification with others, role models

B.4 Raw Quantitative Data

Table 37: 6MWT and Self-reported Exercise

Table 38: Self-efficacy, Self-management Behaviours, Shortness of Breath, Exercise Participation, Stage of Change

Table 39: Health-related Quality of Life- Physical Function, Role Physical, Bodily Pain, General Health, Vitality

Table 40: Health-related Quality of Life-Social Function, Role Emotional, Mental Health, Physical Component Summary, Mental Component Summary

Table 41: Study Participants versus the Balance of Referrals

Table 37: Raw Data: Six-Minute Walk Test, Self-Reported Exercise

Participant	Allocation	6-Minute Walk Test		Self-reported Exercise Duration All Exercise		Self-reported Exercise Frequency All Exercise		Self-reported Exercise Duration Moderate Exercise		Self-reported Exercise Frequency Moderate Exercise	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1001	Intervention	54.0	114.0	.00	2.00	.00	115.00	.00	.50	.00	.00
1002	Control	281.0	missing	.00	.00	.00	.00	.00	.00	.00	.00
1003	Control	350.0	332.0	6.75	6.50	15.00	16.00	1.50	.50	3.00	1.00
1004	Intervention	422.0	437.0	23.00	29.75	27.00	37.00	.00	12.00	7.00	18.00
1005	Intervention	428.0	506.0	4.25	4.75	25.00	30.00	1.00	3.25	11.00	16.00
1006	Intervention	400.0	missing	2.25	.00	5.00	.00	.00	.00	.00	.00
1007	Control	182.0	183.0	2.25	5.25	5.00	13.00	.00	1.75	.00	3.00
1008	Control	105.0	303.0	9.25	10.00	8.00	25.00	.00	.50	.00	5.00
1009	Intervention	425.0	550.0	5.75	2.75	7.00	16.00	.00	.50	.00	1.00
1010	Control	380.0	457.0	2.00	6.75	5.00	11.00	.50	2.25	1.00	3.00
1011	Intervention	100.0	75.0	1.75	1.00	3.00	14.00	.00	.00	.00	.00
1012	Control	missing	missing	2.00	.00	19.00	.00	.00	.00	.00	.00
1013	Control	335.0	337.0	3.50	9.25	2.00	8.00	.00	5.75	.00	3.00
1014	Intervention	333.0	404.0	.50	4.00	6.00	25.00	.00	.00	.00	.00
1015	Intervention	missing	missing	.00	.00	.00	.00	.00	.00	.00	.00
1016	Control	400.0	473.0	.00	10.50	.00	13.00	.00	3.50	.00	3.00
1017	Control	427.0	500.0	18.50	23.00	22.00	32.00	5.50	15.75	11.00	19.00
1018	Intervention	445.0	428.0	8.75	11.75	12.00	16.00	.50	1.50	2.00	2.00
1019	Intervention	395.0	424.0	26.00	34.00	24.00	18.00	19.50	30.75	10.00	10.00
1020	Control	500.0	missing	19.00	.00	25.00	.00	3.75	.00	8.00	.00
1021	Control	427.0	475.0	16.25	11.50	10.00	22.00	4.75	2.25	5.00	11.00
1022	Control	430.0	425.0	17.25	15.00	23.00	13.00	6.25	13.25	6.00	12.00
1023	Control	385.0	305.0	5.25	10.00	20.00	24.00	3.25	1.00	12.00	6.00
1024	Intervention	329.0	408.0	.00	10.75	.00	9.00	.00	.50	.00	1.00
1025	Intervention	420.0	391.0	5.25	9.75	6.00	13.00	1.75	6.25	2.00	5.00
1026	Intervention	243.0	missing	1.00	.00	8.00	.00	.00	.00	.00	.00
1027	Control	295.0	335.0	15.50	4.25	11.00	8.00	.00	.00	.00	.00
1028	Intervention	300.0	340.0	1.75	12.50	7.00	21.00	.00	2.75	.00	2.00
1029	Intervention	275.0	250.0	5.25	11.25	14.00	23.00	1.00	3.75	4.00	5.00
1030	Control	309.0	missing	4.00	.00	10.00	.00	1.75	.00	2.00	.00

Table 37 continued

Participant	Allocation	6-Minute Walk Test		Self-reported Exercise Duration All Exercise		Self-reported Exercise Frequency All Exercise		Self-reported Exercise Duration Moderate Exercise		Self-reported Exercise Frequency Moderate Exercise	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1031	Intervention	305.0	missing	.00	.00	.00	.00	.00	.00	.00	.00
1033	Control	409.0	487.0	3.25	11.50	14.00	36.00	.50	2.75	2.00	4.00
1034	Intervention	369.0	308.0	5.50	6.75	22.00	10.00	2.25	3.50	11.00	3.00
1035	Intervention	125.0	228.0	7.75	4.00	6.00	22.00	5.50	1.75	3.00	1.00
1036	Intervention	316.0	359.0	1.75	11.75	5.00	20.00	.00	.50	.00	3.00
1037	Control	325.0	240.0	4.00	7.75	10.00	21.00	.50	2.25	2.00	4.00
1038	Control	397.0	345.0	14.50	17.25	35.00	36.00	5.25	4.00	14.00	4.00
1039	Control	489.0	missing	52.25	.00	37.00	.00	9.75	.00	8.00	.00
1040	Control	450.0	496.0	4.00	12.75	7.00	15.00	.00	5.50	1.00	6.00
1041	Intervention	320.0	275.0	1.50	3.75	6.00	21.00	.50	1.50	2.00	6.00
1042	Control	360.0	430.0	16.75	31.75	22.00	35.00	1.75	11.00	3.00	8.00
1043	Control	276.0	358.0	13.00	6.75	10.00	13.00	10.25	2.25	5.00	3.00
1044	Intervention	552.0	561.0	18.50	36.50	30.00	33.00	11.25	25.25	20.00	19.00
1045	Intervention	456.0	467.0	1.50	4.75	5.00	17.00	.50	2.75	2.00	4.00
1047	Control	486.0	454.0	13.50	14.50	18.00	32.00	1.75	9.00	6.00	22.00
1048	Control	305.0	missing	7.25	.00	6.00	.00	3.75	.00	.00	.00
1049	Intervention	350.0	320.0	7.25	7.25	13.00	8.00	.00	2.75	.00	3.00
1050	Intervention	340.0	not recorded	3.25	.00	10.00	.00	.50	.00	1.00	.00
1051	Control	207.0	263.0	.00	.00	.00	.00	.00	.00	.00	.00
1053	Intervention	150.0	missing	.00	1.00	.00	4.00	.00	.00	.00	.00
1054	Control	375.0	427.0	23.50	13.25	15.00	15.00	.50	3.50	2.00	4.00
1055	Control	75.0	85.0	3.50	5.75	9.00	15.00	.00	.00	.00	.00
1056	Intervention	309.0	190.0	.00	2.50	.00	29.00	.00	.00	.00	.00
1057	Intervention	500.0	519.0	5.00	18.25	20.00	35.00	2.75	10.50	10.00	17.00
1058	Intervention	350.0	394.0	6.25	8.25	31.00	36.00	1.75	1.50	7.00	5.00
1059	Control	500.0	507.0	22.50	16.75	24.00	20.00	3.50	5.50	3.00	9.00
1060	Control	387.0	missing	6.50	.00	21.00	.00	1.50	.00	5.00	.00
1061	Intervention	432.0	457.0	14.25	6.25	14.00	8.00	8.50	2.75	6.00	4.00
1062	Intervention	430.0	460.0	18.25	14.50	33.00	28.00	7.50	7.00	6.00	11.00
1063	Intervention	443.0	480.0	12.25	16.75	49.00	45.00	4.25	9.00	19.00	22.00
1064	Control	370.0	350.0	22.50	13.00	19.00	20.00	7.50	9.50	10.00	8.00
1065	Intervention	415.0	446.0	2.75	18.00	11.00	25.00	.00	9.25	2.00	12.00
1066	Control	375.0	425.0	2.25	13.25	10.00	9.00	.00	.00	.00	.00

Table 37 continued

Participant	Allocation	6-Minute Walk Test		Self-reported Exercise Duration All Exercise		Self-reported Exercise Frequency All Exercise		Self-reported Exercise Duration Moderate Exercise		Self-reported Exercise Frequency Moderate Exercise	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1067	Intervention	379.0	390.0	8.75	13.50	23.00	24.00	7.75	2.25	13.00	.00
1068	Intervention	380.0	358.0	7.00	9.50	14.00	25.00	3.50	4.50	8.00	
1069	Intervention	517.0	missing	12.25	.00	7.00	.00	2.75	.00	3.00	
1070	Control	405.0	430.0	11.00	9.25	13.00	21.00	1.75	2.25	1.00	3.00
1071	Control	346.0	330.0	.50	9.50	7.00	11.00	.00	.00	.00	.00
1072	Intervention	256.0	250.0	9.50	13.25	8.00	19.00	.00	2.25	.00	2.00
1073	Control	261.0	missing	8.00	.00	10.00	.00	.50	.00	1.00	.00
1074	Control	290.0	365.0	3.25	6.00	20.00	19.00	.00	.50	.00	3.00
1075	Intervention	175.0	217.0	2.75	6.75	6.00	9.00	.00	2.75	.00	3.00
1076	Control	300.0	281.0	14.50	25.75	23.00	38.00	3.50	7.50	6.00	8.00
1077	Intervention	370.0	398.0	7.50	4.75	13.00	19.00	1.50	1.50	7.00	8.00
1078	Intervention	425.0	416.0	4.00	4.25	15.00	20.00	.00	.50	.00	1.00
1079	Intervention	436.0	491.0	2.25	6.25	9.00	14.00	.00	1.00	.00	1.00
1080	Intervention	512.0	594.0	5.75	3.75	8.00	15.00	.00	1.75	.00	4.00
1081	Control	422.0	415.0	9.25	3.75	7.00	5.00	7.50	2.75	2.00	3.00
1082	Control	442.0	466.0	17.75	25.25	11.00	23.00	.50	1.00	2.00	5.00
1083	Intervention	68.0	155.0	1.00	2.50	9.00	6.00	.00	1.50	.00	2.00
1084	Intervention	517.0	533.0	9.50	11.50	36.00	46.00	2.75	5.50	7.00	11.00
1085	Control	375.0	420.0	15.50	11.75	37.00	50.00	1.50	7.00	14.00	22.00
1086	Control	265.0	missing	11.50	.00	59.00	.00	5.75	.00	23.00	.00
1087	Control	423.0	missing	19.00	.00	26.00	.00	.00	.00	7.00	.00

Table 38: Raw Data: Self-efficacy, Self-management Behaviours, Shortness of Breath, Exercise Participation, Stage of Change

Participant	Allocation	Self-efficacy		Self-management Behaviours		Shortness of Breath Severity		Shortness of Breath Frequency		Exercise Participation		Stage of Change	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1001	Intervention	4.17	3.83	6.29	6.57	9.9	9.5	9.9	6.2	no	no	contemplation	contemplation
1002	Control	3.33	missing	5.64	missing	6.5	missing	6.7	missing	no	missing	contemplation	missing
1003	Control	1.72	3.06	5.36	7.64	9.8	9.7	10.0	9.9	no	yes	preparation	maintenance
1004	Intervention	4.78	1.89	7.86	8.00	4.1	4.9	3.2	4.9	no	no	preparation	preparation
1005	Intervention	3.33	3.50	5.14	6.21	4.6	3.0	7.1	2.5	yes	yes	maintenance	maintenance
1006	Intervention	1.00	missing	5.86	missing	10.0	missing	10.0	missing	no	missing	contemplation	missing
1007	Control	1.00	2.28	6.07	6.00	9.5	7.8	9.6	7.6	no	no	precontemplation	contemplation
1008	Control	4.83	3.44	7.00	7.71	9.6	10.0	9.6	10.0	no	yes	contemplation	maintenance
1009	Intervention	3.17	2.56	6.29	6.43	9.8	9.7	4.9	10.0	no	yes	contemplation	action
1010	Control	1.89	1.56	5.64	5.00	5.7	4.4	5.2	4.6	no	no	precontemplation	contemplation
1011	Intervention	1.72	1.83	6.50	6.79	9.0	8.4	8.8	9.6	no	no	contemplation	contemplation
1012	Control	2.28	missing	7.14	missing	5.3	missing	4.5	missing	yes	missing	action	missing
1013	Control	1.94	2.06	4.00	4.00	4.5	6.3	2.2	6.0	no	no	contemplation	preparation
1014	Intervention	2.83	2.00	5.93	5.21	5.3	6.6	5.2	4.8	yes	no	maintenance	contemplation
1015	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing
1016	Control	missing	1.94	missing	6.00	missing	4.7	missing	4.5	missing	no	missing	action
1017	Control	3.33	1.28	6.57	6.86	3.6	9.1	4.9	9.0	no	no	preparation	contemplation
1018	Intervention	3.33	2.56	4.00	6.43	6.3	3.4	6.0	4.8	no	yes	contemplation	contemplation
1019	Intervention	4.61	4.28	6.57	6.50	2.4	6.1	.9	6.5	yes	yes	maintenance	maintenance
1020	Control	2.39	missing	7.29	missing	9.4	missing	2.3	missing	no	missing	contemplation	missing
1021	Control	3.00	3.17	6.43	7.50	6.7	2.5	5.2	1.0	no	no	contemplation	contemplation
1022	Control	3.00	4.33	4.00	3.21	9.6	9.8	9.6	10.0	no	missing	contemplation	precontemplation
1023	Control	2.33	5.00	6.79	7.14	5.0	10.0	5.6	10.0	no	yes	contemplation	contemplation
1024	Intervention	1.89	1.50	6.71	6.64	6.5	8.1	8.0	8.4	no	no	contemplation	contemplation
1025	Intervention	3.56	4.67	5.50	5.57	7.6	8.2	8.2	8.5	yes	no	action	precontemplation
1026	Intervention	1.00	missing	5.86	missing	6.7	missing	6.4	missing	no	missing	precontemplation	missing
1027	Control	3.50	1.00	6.43	6.57	8.3	9.8	7.3	9.7	no	no	precontemplation	precontemplation
1028	Intervention	1.00	4.56	7.29	7.43	6.1	3.1	6.3	3.4	no	yes	contemplation	action
1029	Intervention	2.44	3.44	7.00	6.93	7.5	8.2	7.9	7.9	no	yes	maintenance	action
1030	Control	1.78	missing	5.29	missing	6.9	missing	8.0	missing	no	missing	precontemplation	missing
1031	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing	not recorded	missing

Table 38 continued

Participant	Allocation	Self-efficacy		Self-management Behaviours		Shortness of Breath Severity		Shortness of Breath Frequency		Exercise Participation		Stage of Change	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1033	Control	1.89	4.50	4.93	7.36	4.2	3.0	4.2	5.3	no	no	contemplation	
1034	Intervention	2.94	2.61	6.50	6.36	9.6	9.9	10.0	10.0	no	no	action	preparation
1035	Intervention	4.50	4.67	7.43	6.93	6.1	5.6	9.6	7.0	no	yes	preparation	action
1036	Intervention	1.61	3.61	4.79	5.36	8.0	5.6	7.9	5.3	no	yes	contemplation	maintenance
1037	Control	3.67	3.00	5.79	6.21	3.5	7.7	3.3	7.9	no	yes	preparation	action
1038	Control	2.28	3.56	7.57	7.50	5.5	7.9	4.3	8.5	no	yes	preparation	maintenance
1039	Control	4.89	missing	6.29	missing	4.5	missing	4.8	missing	yes	missing	action	missing
1040	Control	5.00	3.94	7.64	7.57	10.0	5.5	8.4	5.6	no	no	contemplation	contemplation
1041	Intervention	3.00	2.78	5.36	7.00	10.0	3.7	10.0	3.8	no	yes	contemplation	action
1042	Control	2.61	3.50	6.57	6.14	4.3	4.2	3.9	3.1	yes	yes	maintenance	maintenance
1043	Control	1.61	2.50	6.14	6.93	8.1	4.9	5.6	3.5	no	no	contemplation	precontemplation
1044	Intervention	3.61	3.11	6.14	6.00	5.6	3.1	1.6	3.1	yes	yes	maintenance	maintenance
1045	Intervention	1.33	1.39	7.14	7.00	7.4	1.1	5.3	1.2	no	no	preparation	contemplation
1047	Control	3.22	2.94	5.29	6.14	6.8	7.3	6.3	8.0	no	yes	precontemplation	contemplation
1048	Control	2.67	missing	5.79	missing	4.9	missing	4.6	missing	no	missing	contemplation	missing
1049	Intervention	2.56	1.61	6.43	6.21	8.8	9.6	9.6	9.8	no	no	contemplation	contemplation
1050	Intervention	1.50	missing	7.29	missing	4.6	missing	4.7	missing	no	missing	preparation	missing
1051	Control	2.22	1.89	6.29	6.29	9.4	9.6	10.0	10.0	no	yes	precontemplation	preparation
1053	Intervention	1.28	1.44	5.93	5.21	10.0	9.5	9.9	9.7	no	no	precontemplation	action
1054	Control	3.22	2.94	7.79	7.64	6.2	7.2	5.5	5.2	no	yes	preparation	action
1055	Control	1.67	1.83	5.29	5.50	9.5	9.6	8.1	6.6	no	no	preparation	preparation
1056	Intervention	3.61	4.00	7.43	6.86	9.9	5.5	4.7	9.9	no	yes	contemplation	preparation
1057	Intervention	2.06	2.83	5.64	6.43	7.3	7.0	8.8	6.3	no	no	contemplation	action
1058	Intervention	3.39	2.33	7.29	6.71	9.8	9.3	5.5	7.9	yes	yes	action	action
1059	Control	4.00	3.89	6.07	6.14	.9	4.7	.9	2.0	yes	yes	action	action
1060	Control	2.22	missing	6.50	missing	4.7	missing	4.3	missing	no	missing	action	missing
1061	Intervention	4.17	4.00	7.29	7.64	6.2	6.3	4.0	6.5	yes	yes	maintenance	maintenance
1062	Intervention	2.89	3.28	6.43	7.36	7.9	7.3	9.6	8.6	no	no	contemplation	action
1063	Intervention	3.44	4.06	6.07	6.71	7.3	6.8	7.7	2.1	yes	yes	maintenance	maintenance
1064	Control	2.33	2.78	6.86	6.86	9.9	5.4	10.0	5.1	no	yes	contemplation	maintenance
1065	Intervention	1.72	3.72	5.57	5.93	5.9	7.4	9.9	7.6	no	yes	preparation	action
1066	Control	2.00	1.83	5.86	5.71	9.1	7.8	9.9	8.9	no	yes	preparation	preparation
1067	Intervention	3.72	4.17	6.57	6.71	3.7	6.5	7.6	6.7	yes	yes	maintenance	maintenance
1068	Intervention	2.83	3.28	4.79	3.71	8.4	4.2	8.2	3.2	yes	yes	action	action

Table 38 continued

Participant	Allocation	Self-efficacy		Self-management Behaviours		Shortness of Breath Severity		Shortness of Breath Frequency		Exercise Participation		Stage of Change	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1069	Intervention	3.50	missing	6.50	missing	6.5	missing	2.5	missing	no	missing	precontemplation	
1070	Control	3.06	4.72	6.21	6.64	1.9	3.2	2.4	3.4	no	yes	contemplation	action
1071	Control	3.28	2.33	6.00	7.14	9.5	5.2	9.2	7.7	no	no	maintenance	preparation
1072	Intervention	1.00	1.56	6.14	6.57	9.5	8.5	9.4	9.5	no	yes	precontemplation	action
1073	Control	3.50	missing	4.43	missing	10.0	missing	10.0	missing	no	missing	contemplation	missing
1074	Control	3.44	2.61	5.93	6.64	7.3	3.9	8.2	5.4	no	no	maintenance	maintenance
1075	Intervention	2.72	4.06	6.50	6.57	9.8	10.0	9.9	10.0	no	no	contemplation	contemplation
1076	Control	2.94	2.83	6.71	7.36	7.9	7.6	7.5	6.8	no	no	contemplation	contemplation
1077	Intervention	2.50	1.72	4.43	5.00	7.5	1.9	9.9	7.3	no	no	preparation	contemplation
1078	Intervention	1.17	3.06	6.00	6.64	8.4	6.9	7.4	6.6	no	no	action	action
1079	Intervention	2.22	2.22	4.21	5.64	3.8	3.7	3.2	3.0	no	yes	preparation	maintenance
1080	Intervention	2.28	3.00	3.50	6.21	4.5	3.8	4.3	2.2	no	yes	preparation	maintenance
1081	Control	1.33	3.50	7.36	6.86	8.7	9.7	8.9	9.6	no	no	contemplation	preparation
1082	Control	1.00	2.89	7.71	6.21	7.8	8.6	4.9	5.4	no	yes	contemplation	action
1083	Intervention	2.61	1.17	3.64	4.64	8.4	3.6	6.5	7.6	no	yes	preparation	action
1084	Intervention	3.78	3.89	6.57	5.64	1.2	4.6	5.2	3.1	yes	yes	action	action
1085	Control	5.00	4.72	7.00	6.86	4.8	5.4	4.6	4.7	yes	yes	action	action
1086	Control	1.94	missing	5.64	missing	6.0	missing	8.2	missing	yes	missing	maintenance	missing
1087	Control	3.61	missing		missing	7.7	missing	7.5	missing	no	missing	maintenance	missing

Table 39: Health-related Quality of Life-Physical Function, Role Physical, Bodily Pain, General Health, Vitality

Participant	Allocation	Physical Function		Role Physical		Bodily Pain		General Health		Vitality	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1001	Intervention	14.94	14.94	17.67	17.65	62.12	62.12	52.93	25.76	48.97	48.97
1002	Control	25.47	missing	37.26	missing	55.36	missing	25.76	missing	27.11	missing
1003	Control	21.26	25.47	25.02	27.45	37.18	41.83	23.38	18.61	39.60	36.48
1004	Intervention	35.99	44.41	54.40	44.60	50.28	51.13	57.70	52.93	61.46	58.33
1005	Intervention	35.99	31.78	56.85	49.51	37.18	51.13	23.38	45.78	39.60	52.09
1006	Intervention	17.05	missing	17.67	missing	29.15	missing	34.10	missing	39.60	missing
1007	Control	23.36	25.47	20.12	34.80	62.12	51.13	30.53	28.15	48.97	48.97
1008	Control	23.36	29.67	27.47	37.25	62.12	51.13	37.68	35.30	55.21	45.85
1009	Intervention	29.67	33.88	29.91	42.15	37.18	62.12	21.00	23.38	39.60	42.72
1010	Control	29.67	31.78	39.71	34.80	62.12	51.13	37.68	35.30	45.85	45.85
1011	Intervention	19.15	21.26	25.02	20.10	62.12	62.12	28.15	25.76	42.72	27.11
1012	Control	25.47	missing	22.57	missing	51.13	missing	30.53	missing	42.72	missing
1013	Control	46.51	21.26	17.67	22.55	32.96	32.96	52.93	49.60	27.11	36.48
1014	Intervention	29.67	27.57	29.91	25.00	62.12	62.12	48.17	38.63	48.97	36.48
1015	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing
1016	Control	missing	38.09	missing	44.60	missing	37.18	missing	43.40	missing	39.60
1017	Control	31.78	33.88	27.47	51.96	55.36	62.12	38.63	43.40	39.60	45.85
1018	Intervention	35.99	46.51	39.71	44.60	55.36	55.36	38.63	36.25	39.60	48.97
1019	Intervention	44.41	48.61	44.61	54.41	55.36	51.13	37.68	30.53	52.09	48.97
1020	Control	35.99	missing	39.71	missing	46.06	missing	30.53	missing	36.48	missing
1021	Control	31.78	38.09	27.47	42.15	46.06	46.06	45.78	50.55	33.36	45.85
1022	Control	27.57	17.05	29.91	34.80	41.83	41.41	37.68	47.21	36.48	39.60
1023	Control	25.47	27.57	25.02	20.10	41.41	24.93	18.61	18.61	33.36	42.72
1024	Intervention	27.57	29.67	37.26	32.35	33.38	37.18	18.61	21.00	42.72	45.85
1025	Intervention	38.09	38.09	32.36	29.90	29.15	24.08	32.91	32.91	48.97	39.60
1026	Intervention	21.26	missing	27.47	missing	50.28	missing	30.53	missing	30.24	missing
1027	Control	27.57	42.30	47.06	56.86	37.61	37.61	42.45	23.38	52.09	45.85
1028	Intervention	25.47	35.99	34.81	44.60	45.64	45.64	25.76	36.25	27.11	30.24
1029	Intervention	31.78	25.47	29.91	32.35	62.12	62.12	32.91	40.06	48.97	39.60
1030	Control	19.15	missing	17.67	missing	19.86	missing	28.15	missing	45.85	missing
1031	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing
1033	Control	23.36	42.30	25.02	49.51	41.41	55.36	18.61	36.25	30.24	45.85
1034	Intervention	19.15	19.15	37.26	37.25	55.36	62.12	18.61	23.38	42.72	42.72
1035	Intervention	25.47	40.20	39.71	42.15	62.12	55.36	35.30	40.06	52.09	58.33

Table 39 continued

Participant	Allocation	Physical Function		Role Physical		Bodily Pain		General Health		Vitality	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1036	Intervention	35.99	27.57	34.81	25.00	51.13	46.06	28.15	30.53	39.60	39.60
1037	Control	35.99	31.78	44.61	37.25	55.36	53.67	45.78	35.30	52.09	48.97
1038	Control	38.09	38.09	34.81	27.45	46.06	62.12	23.38	23.38	42.72	36.48
1039	Control	44.41	missing	47.06	missing	51.13	missing	36.25	missing	48.97	missing
1040	Control	27.57	35.99	37.26	29.90	62.12	46.06	28.15	18.61	36.48	48.97
1041	Intervention	17.05	25.47	27.47	39.70	41.83	41.83	42.45	37.68	45.85	58.33
1042	Control	33.88	38.09	47.06	47.06	37.18	41.41	41.02	41.02	33.36	61.46
1043	Control	23.36	25.47	17.67	27.45	62.12	62.12	18.61	18.61	48.97	52.09
1044	Intervention	50.72	46.51	39.71	42.15	62.12	51.13	44.83	48.17	52.09	48.97
1045	Intervention	27.57	29.67	37.26	37.25	62.12	37.18	36.25	30.53	52.09	36.48
1047	Control	42.30	27.57	32.36	32.35	33.38	46.06	28.15	32.91	39.60	39.60
1048	Control	27.57	missing	29.91	missing	62.12	missing	35.30	missing	45.85	missing
1049	Intervention	27.57	29.67	29.91	27.45	41.41	41.83	21.00	25.76	33.36	36.48
1050	Intervention	17.05	missing	17.67	missing	24.93	missing	35.30	missing	42.72	missing
1051	Control	17.05	14.94	20.12	17.65	32.96	19.86	21.00	16.23	27.11	30.24
1053	Intervention	25.47	25.47	17.67	34.80	46.06	46.90	28.15	23.38	36.48	36.48
1054	Control	29.67	40.20	47.06	39.70	37.18	29.15	42.45	42.45	48.97	52.09
1055	Control	14.94	14.94	27.47	27.45	28.73	32.96	21.00	30.53	20.87	33.36
1056	Intervention	31.78	25.47	37.26	37.25	45.64	37.18	18.61	32.91	45.85	39.60
1057	Intervention	31.78	33.88	37.26	37.25	37.18	37.18	18.61	25.76	42.72	45.85
1058	Intervention	33.88	35.99	27.47	32.35	28.31	46.90	32.91	18.61	42.72	36.48
1059	Control	35.99	35.99	56.85	44.60	62.12	53.67	38.63	38.63	58.33	58.33
1060	Control	40.20	missing	32.36	missing	50.28	missing	43.40	missing	52.09	missing
1061	Intervention	42.30	33.88	37.26	34.80	46.06	46.06	31.48	41.02	52.09	55.21
1062	Intervention	27.57	29.67	25.02	32.35	29.15	62.12	18.61	23.38	39.60	45.85
1063	Intervention	27.57	38.09	56.85	54.41	50.28	55.36	26.72	36.25	33.36	42.72
1064	Control	21.26	31.78	42.16	37.25	50.28	37.18	49.60	55.32	58.33	48.97
1065	Intervention	23.36	25.47	17.67	37.25	37.18	37.18	21.00	32.91	20.87	27.11
1066	Control	14.94	29.67	37.26	37.25	37.18	46.06	23.38	23.38	23.99	33.36
1067	Intervention	35.99	33.88	29.91	32.35	37.18	41.41	38.63	38.63	48.97	55.21
1068	Intervention	33.88	38.09	29.91	32.35	53.67	46.90	37.68	36.25	33.36	48.97
1069	Intervention	42.30	missing	44.61	missing	55.36	missing	35.30	missing	45.85	missing
1070	Control	29.67	29.67	29.91	32.35	32.96	37.61	37.68	32.91	39.60	33.36
1071	Control	17.05	23.36	32.36	42.15	46.06	46.06	31.48	25.76	39.60	42.72
1072	Intervention	19.15	19.15	17.67	17.65	46.06	46.90	25.76	16.23	33.36	27.11

Table 39 continued

Participant	Allocation	Physical Function		Role Physical		Bodily Pain		General Health		Vitality	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1073	Control	31.78	missing	34.81	missing	62.12	missing	32.91	missing	52.09	missing
1074	Control	27.57	29.67	32.36	44.60	37.18	50.29	23.38	21.00	30.24	55.21
1075	Intervention	17.05	21.26	25.02	17.65	37.18	62.12	18.61	16.23	45.85	27.11
1076	Control	27.57	29.67	27.47	37.25	29.15	29.15	25.76	25.76	36.48	36.48
1077	Intervention	35.99	33.88	22.57	27.45	24.93	29.15	18.61	18.61	20.87	33.36
1078	Intervention	23.36	31.78	17.67	20.10	41.83	51.13	16.23	18.61	42.72	45.85
1079	Intervention	35.99	40.20	32.36	47.06	62.12	51.13	26.72	29.10	48.97	55.21
1080	Intervention	14.94	14.94	27.47	37.25	46.06	62.12	28.15	32.91	20.87	45.85
1081	Control	21.26	14.94	29.91	27.45	32.96	33.38	37.68	25.76	36.48	42.72
1082	Control	40.20	31.78	22.57	25.00	37.61	29.15	30.53	18.61	52.09	39.60
1083	Intervention	25.47	25.47	25.02	32.35	37.18	37.61	30.53	28.15	36.48	45.85
1084	Intervention	44.41	40.20	39.71	47.06	37.18	37.18	25.76	31.48	48.97	48.97
1085	Control	40.20	48.61	32.36	54.41	41.41	45.64	30.53	45.78	42.72	55.21
1086	Control	27.57	missing	37.26	missing	41.41	missing	28.15	missing	30.24	missing
1087	Control	31.78	missing	22.57	missing	41.83	missing	23.38	missing	39.60	missing

Table 40: Health-related Quality of Life Social Function, Role Emotional, Mental Health, Physical Component Summary, Mental Component Summary

Participant	Allocation	Social Function		Role Emotional		Mental Health		Physical Component Summary		Mental Component Summary	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1001	Intervention	13.22	51.40	55.88	44.22	52.82	44.31	26.86	23.88	54.62	56.14
1002	Control	29.58	missing	55.88	missing	44.38	missing	30.41	missing	46.02	missing
1003	Control	45.94	45.94	24.78	40.33	41.56	55.70	24.77	21.51	42.77	53.98
1004	Intervention	56.85	56.85	55.88	55.88	64.09	64.24	43.65	42.77	66.46	64.99
1005	Intervention	56.85	51.40	55.88	55.88	55.64	58.55	33.04	38.46	58.73	61.73
1006	Intervention	29.58	missing	9.23	missing	35.93	missing	24.18	missing	31.38	missing
1007	Control	45.94	29.58	55.88	24.78	50.01	35.77	26.07	37.24	60.16	34.24
1008	Control	51.40	40.49	20.89	32.56	64.09	47.16	34.18	37.52	53.73	43.90
1009	Intervention	45.94	56.85	36.44	55.88	50.01	50.01	25.37	36.22	49.43	56.60
1010	Control	51.40	45.94	32.56	28.67	58.46	50.01	39.90	37.63	50.89	44.86
1011	Intervention	35.03	24.13	17.01	32.56	52.82	44.31	32.17	29.24	40.65	36.85
1012	Control	35.03	.	9.23	.	41.56	.	35.07	.	31.69	.
1013	Control	18.67	29.58	24.78	20.89	21.85	35.77	43.14	31.12	17.97	33.52
1014	Intervention	40.49	51.40	9.23	17.01	35.93	35.77	48.70	41.76	28.67	33.28
1015	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing
1016	Control	missing	56.85	missing	36.44	missing	44.31	missing	40.83	missing	45.53
1017	Control	40.49	40.49	32.56	51.99	33.11	30.08	40.09	49.97	35.85	40.15
1018	Intervention	51.40	56.85	36.44	55.88	50.01	52.85	41.61	43.06	46.20	56.68
1019	Intervention	56.85	56.85	48.10	51.99	50.01	58.55	44.73	44.13	53.14	56.54
1020	Control	40.49	missing	40.33	missing	41.56	missing	37.75	missing	41.14	missing
1021	Control	35.03	56.85	44.22	48.10	35.93	47.16	35.92	41.89	40.13	52.76
1022	Control	35.03	45.94	9.23	36.44	47.19	58.55	35.96	27.74	32.36	55.02
1023	Control	35.03	29.58	9.23	28.67	35.93	38.62	30.85	20.72	27.58	39.85
1024	Intervention	51.40	40.49	32.56	32.56	50.01	47.16	26.04	27.80	49.93	46.08
1025	Intervention	40.49	45.94	55.88	55.88	55.64	58.55	25.54	22.13	59.70	61.13
1026	Intervention	40.49	missing	40.33	missing	47.19	missing	27.13	missing	46.90	missing
1027	Control	51.40	51.40	55.88	55.88	47.19	47.16	33.17	37.93	58.90	53.13
1028	Intervention	56.85	56.85	51.99	48.10	52.82	52.85	25.14	36.47	57.01	52.27
1029	Intervention	56.85	45.94	55.88	55.88	55.64	64.24	32.35	30.26	62.65	62.65
1030	Control	18.67	missing	9.23	missing	27.48	missing	23.46	missing	26.32	missing
1031	Intervention	missing	missing	missing	missing	missing	missing	missing	missing	missing	missing
1033	Control	29.58	51.40	48.10	55.88	41.56	58.55	21.20	41.71	45.47	57.58

Table 40 continued

Participant	Allocation	Social Function		Role Emotional		Mental Health		Physical Component Summary		Mental Component Summary	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1034	Intervention	51.40	40.49	32.56	32.56	50.01	41.47	29.45	34.72	49.73	41.96
1035	Intervention	56.85	56.85	48.10	40.33	64.09	64.24	33.42	41.25	64.32	59.31
1036	Intervention	56.85	35.03	44.22	55.88	55.64	47.16	33.16	24.90	54.95	53.65
1037	Control	56.85	51.40	44.22	32.56	52.82	50.01	43.31	38.60	54.63	48.20
1038	Control	40.49	45.94	48.10	55.88	58.46	55.70	30.09	31.50	54.43	55.78
1039	Control	45.94	missing	51.99	missing	55.64	missing	41.90	missing	54.03	missing
1040	Control	45.94	56.85	55.88	55.88	50.01	58.55	32.94	24.84	54.18	64.83
1041	Intervention	40.49	35.03	32.56	28.67	41.56	50.01	28.80	34.76	46.06	46.58
1042	Control	18.67	56.85	44.22	55.88	44.38	61.40	37.95	35.61	37.88	66.64
1043	Control	40.49	29.58	55.88	44.22	52.82	55.70	21.66	27.77	60.55	52.97
1044	Intervention	56.85	51.40	36.44	28.67	61.27	50.01	49.37	49.72	51.93	42.57
1045	Intervention	56.85	56.85	32.56	55.88	55.64	58.55	38.54	24.54	53.27	63.12
1047	Control	35.03	51.40	32.56	32.56	41.56	47.16	34.85	32.44	37.76	46.98
1048	Control	56.85	missing	40.33	missing	50.01	missing	35.30	missing	53.36	missing
1049	Intervention	40.49	40.49	40.33	36.44	50.01	55.70	24.94	25.86	48.26	49.75
1050	Intervention	24.13	missing	9.23	missing	27.48	missing	25.84	missing	26.93	missing
1051	Control	24.13	18.67	9.23	9.23	50.01	52.85	20.27	12.65	33.34	36.12
1053	Intervention	40.49	40.49	17.01	13.12	50.01	44.31	27.57	34.64	40.30	33.76
1054	Control	35.03	35.03	48.10	32.56	41.56	50.01	36.70	37.24	47.21	44.57
1055	Control	18.67	24.13	32.56	20.89	38.74	32.92	18.49	25.98	35.05	31.10
1056	Intervention	56.85	35.03	55.88	40.33	41.56	41.47	29.15	30.32	55.99	43.96
1057	Intervention	35.03	40.49	32.56	44.22	33.11	44.31	32.89	30.88	35.99	48.13
1058	Intervention	24.13	45.94	40.33	36.44	30.30	32.92	30.30	35.02	36.43	37.83
1059	Control	56.85	56.85	55.88	48.10	52.82	52.85	45.90	40.42	59.10	58.06
1060	Control	45.94	missing	36.44	missing	44.38	missing	42.03	missing	45.29	missing
1061	Intervention	40.49	40.49	32.56	32.56	50.01	47.16	39.87	38.53	44.38	45.84
1062	Intervention	24.13	35.03	51.99	55.88	55.64	55.70	15.54	30.01	54.96	56.38
1063	Intervention	51.40	56.85	40.33	48.10	47.19	50.01	39.18	44.87	45.55	51.20
1064	Control	56.85	45.94	55.88	28.67	64.09	30.08	30.99	43.50	70.75	36.76
1065	Intervention	18.67	35.03	9.23	20.89	30.30	32.92	27.65	35.56	19.27	28.48
1066	Control	35.03	45.94	13.12	32.56	24.66	41.47	32.02	33.78	22.84	40.37
1067	Intervention	29.58	40.49	28.67	32.56	52.82	50.01	33.70	34.97	43.51	48.00
1068	Intervention	45.94	35.03	24.78	28.67	55.64	55.70	37.37	37.27	42.81	44.65
1069	Intervention	56.85	missing	55.88	missing	52.82	missing	40.96	missing	56.93	missing

Table 40 continued

Participant	Allocation	Social Function		Role Emotional		Mental Health		Physical Component Summary		Mental Component Summary	
		baseline	post	baseline	post	baseline	post	baseline	post	baseline	post
1070	Control	56.85	56.85	55.88	55.88	58.46	58.55	22.51	23.46	65.06	62.91
1071	Control	45.94	51.40	32.56	55.88	47.19	52.85	27.67	26.68	47.95	60.44
1072	Intervention	24.13	40.49	44.22	9.23	50.01	38.62	19.11	25.87	48.47	30.81
1073	Control	45.94	missing	36.44	missing	64.09	missing	36.11	missing	55.51	missing
1074	Control	40.49	56.85	36.44	51.99	52.82	58.55	25.09	30.19	47.28	63.81
1075	Intervention	40.49	13.22	9.23	17.01	64.09	61.40	20.03	25.34	48.01	35.83
1076	Control	29.58	35.03	36.44	51.99	50.01	55.70	22.29	22.33	45.80	55.06
1077	Intervention	24.13	29.58	20.89	32.56	21.85	38.62	29.82	26.30	19.42	36.56
1078	Intervention	56.85	51.40	55.88	55.88	61.27	58.55	12.46	21.17	69.59	64.32
1079	Intervention	56.85	51.40	55.88	55.88	58.46	50.01	32.83	38.96	62.84	56.99
1080	Intervention	24.13	35.03	20.89	20.89	24.66	38.62	31.09	38.31	22.82	35.62
1081	Control	29.58	40.49	36.44	36.44	47.19	47.16	25.28	18.98	45.02	51.32
1082	Control	40.49	51.40	55.88	44.22	58.46	41.47	24.55	21.71	61.74	51.11
1083	Intervention	40.49	35.03	9.23	13.12	21.85	27.23	35.63	36.06	23.17	27.42
1084	Intervention	45.94	51.40	44.22	44.22	38.74	32.92	37.49	40.92	44.87	43.57
1085	Control	56.85	56.85	32.56	44.22	52.82	58.55	34.54	47.87	49.50	54.93
1086	Control	40.49	missing	32.56	missing	24.66	missing	36.30	missing	30.82	missing
1087	Control	35.03	missing	36.44	missing	38.74	missing	28.32	missing	40.96	missing

B.5 Outcomes: Study Participants versus Balance of Referrals

Table 41: Study Participants versus the Balance of Referrals

Variable	Population Referred N = 316	Participants N = 84	Other Referrals N = 232	p value P versus OR
Female	152 (48.1%)	39 (46.4%)	113 (48.7%)	0.965
Age (years)	66.5 ± 11.65 (65.2 – 67.8) 7 (2.2%) missing	65.8 ± 9.35	66.8 ± 12.41 (65.2 – 68.5) 7 (3.01%) missing	0.402
Not married	114 (36.1%)	34 (40.5%)	80 (39.0%)	0.923
Married	175 (55.4%) 27 (8.5% missing)	50 (59.5%)	125 (61.0%) 27 missing	
Referrals: Private, Primary Health	95 (30.1%)	37 (44.0%)	59 (26.6%)	0.008
Wards	101 (32.0%)	19 (22.6%)	81 (36.5%)	
Clinics	110 (34.8%) 10 (3.2%) missing	28 (33.3%)	82 (36.9%)	
Socioeconomic Status:				0.402
above median	125 (41.7%)	37 (46.3%)	88 (40.0%)	
below median	175 (58.3%) 16 missing	43 (53.8%) 4 missing	132 (60.0%) 12 missing	0.051
COPD Grade: Mild (60–80%)	77 (24.4%)	20 (29.0%)	55 (44.0%)	
Moderate (40–59%)	47 (14.9%)	16 (23.2%)	31 (24.8%)	
Severe (< 40%)	73 (23.1%) 119 (37.7%) missing	33 (47.8%) 15 missing	39 (31.2%) 38 missing	

Note: Data are reported as either raw number (percentage) within study group status and as means ± standard deviations. The p-values are from t tests or chi-square analyses. P = participant, OR = other referral.

Appendix C: Acronyms

COPD	Chronic Obstructive Pulmonary Disease
CDSMP	Chronic Disease Self-Management Programme
SaO ₂	Oxygen Saturation
HR	Heart Rate
BP	Blood Pressure
6MWT	Six-Minute Walk Test
RPE	Rating of Perceived Exertion
ATS	American Thoracic Society
HRQoL	Health-Related Quality of Life
ICC	Intraclass Correlation Coefficient
VAS	Visual Analogue Scale
SF-36v2	Short-Form 36 Version 2
SGRQ	St. George's Respiratory Questionnaire

Appendix D: Related Conference Abstracts, Professional Development

D.1 Related Conference Abstracts

D.2 Related Professional Development

D.1 Related Conference Abstracts

Australian Physiotherapy Association Conference Gerontology Stream. Cairns, Australia. October, 2007

(Invited plenary session speaker)

'UP AND 'RUNNING' STILL: CHRONIC DISEASE SELF-MANAGEMENT (CDSM) APPROACHES FOR OLDER PEOPLE

Helen Cameron-Tucker, Coordinator, Cardiopulmonary Rehabilitation and Stanford Chronic Disease Self-Management (CDSMP) Master Trainer, Department of Physiotherapy, Royal Hobart Hospital and PhD Candidate, Menzies Research Institute and Faculty of Education, University of Tasmania, Hobart, Tasmania.

Introduction: With increasing age comes an expected increasing incidence and burden of chronic conditions (Newman, Steed & Mulligan 2004). Governments and health professionals recognise that a model of healthcare designed to react to acute presentations is not optimal for helping people live with long term conditions on a daily basis.

Managing a long term condition requires the adoption or maintenance of health-related behaviours and consideration of the person's self-perception. Self-management interventions supported by behaviour-change theories are being adopted to assist people in this regard. Self-management is a dynamic process referring to an individual's capability and confidence to deal with the impact of living with a chronic condition on all aspects of his /her life: a sense of self and their medical, emotional and social domains.

This paper will focus on a study of the Stanford CDSMP (Lorig, Sobel et al. 1999) with or without supervised exercise (CDSMP±Ex) for adults with chronic obstructive pulmonary disease (COPD), and relate this to how these older individuals are indeed, 'up and running still'.

Purpose: We offer the CDSMP instead of traditional cardiopulmonary rehabilitation at the Royal Hobart Hospital. As it has no supervised exercise, we sought to evaluate the effect of supervised exercise with the CDSMP on physical capacity for people with COPD. We also sought to understand the experiences of participants attending the CDSMP±Ex.

Method: A prospective randomised controlled clinical trial of the CDSMP±Ex was conducted, using mixed methods. Physical capacity was measured by the 6 minute walk test. Over two years a purposeful sample of fourteen men and six women with severe COPD were interviewed about their experience of COPD, the CDSMP and supervised exercise.

Outcomes: Quantitative data analysis is being undertaken.

The qualitative study Findings are presented. (1) Participants revealed self-developed strategies (planning and pacing, acceptance of limitations) for managing COPD. (2) Following the CDSMP, participants included adoption of health behaviours, self-reliance and self-consideration in their meaning of self-management. (3) Common social processes (influence of role models, social comparison and relief from social isolation) surrounded the CDSMP and supervised exercise, were as important as the programme content and exercise. In particular, participants indicated that action planning enhanced perceived personal control. (3) A *choice* of supervised exercise was overwhelmingly recommended with the CDSMP. (4) Participants indicated a preference for the CDSMP instead of traditional approaches. (5) The CDSMP and supervised exercise experiences emerged as participant-centred, in contrast to other healthcare encounters participants experienced.

Conclusions: Older people can augment their self-developed strategies for managing the impact of COPD on their lives. Common social processes act across the CDSMP and supervised exercise. Supervised exercise should be offered with the CDSMP for people with COPD. Participants prefer the CDSMP structure. A participant-centred healthcare approach is essential for healthcare interactions, maximising individuals' participation in their own healthcare as well as life. (References included in conference proceedings)

Australian Disease Management Conference. Melbourne, Australia. September

(Invited Speaker)

**OUTCOMES OF CHRONIC DISEASE SELF-MANAGEMENT (CDSM) APPROACHES AT THE
ROYAL HOBART HOSPITAL (RHH): THE PEAKS AND PITFALLS**

Helen Cameron-Tucker, Department of Physiotherapy, Royal Hobart Hospital, Hobart, Tasmania and Menzies Research Institute and Faculty of Education, University of Tasmania. Acknowledgments: Australian Physiotherapy Research Foundation Beryl Haynes Memorial Fund and Royal Hobart Hospital Research Foundation. cameronh@utas.edu.au

Purpose: We sought to implement, evaluate and sustain CDSM in the RHH.

Methodology: 1) Management supported training of staff as Stanford CDSMP leaders. CDSMP was offered instead of cardiopulmonary and cardiac rehabilitation. Health status, health behaviours and participant satisfaction was evaluated over 6 months by self-administered questionnaires. A project team oversaw the initial implementation of the CDSMP. Focus groups are held with leaders. Ongoing support is provided for leader development and service delivery. 2) Management supports collaborative research with the University. (a) PhD research investigating the CDSMP with or without supervised exercise (CDSMP±Ex) has been conducted within clinical practice. Semi-structured interviews were conducted post CDSMP. Physical capacity was measured by 6 minute walk test (6MWT) and self-reported exercise by self-administered questionnaire. (b) Volunteer staff were trained in mentoring to facilitate CDSM for people with cystic fibrosis. Training was over 12 hours, during work time. Mentoring time was incorporated into usual clinical hours. 3) Integration of CDSM into usual care is evaluated and reported as case studies.

Results: 1) Eighteen health professionals were trained in 2004.remain active.

Cognitive symptom management improved ($p=0.006$). Shortness of breath, depression and self-efficacy for managing chronic conditions showed small improvements. Pain, general health, fatigue and stretching and strengthening exercises did not change. Aerobic exercise decreased. Participant feedback suggested a preference for condition-specific groups. Leaders report the need for dedicated time to deliver and evaluate the service. 2a) PhD research suggests that participants be offered a choice of attending supervised exercise. Participants endorsed condition-specific groups and health professionals as leaders. For the total group post CDSMP±Ex, 6MWT increased but not significantly. Duration of self-reported moderate exercise increased ($p=.004$) as did frequency ($p=.010$). 2b) Five RHH staff volunteered as mentors. Staff reported difficulty in accommodating mentoring time in usual hours. 3) Participants who do not or cannot attend groups are offered assessment with telephone follow-up of collaboratively defined goals and action plans.

Conclusions: CDSMP can be integrated into hospital rehabilitation services. Condition-specific groups are successful. Supervised exercise may not be necessary for all participants. Leaders require ongoing managerial support and training for service delivery. Either dedicated time or dedicated staff allocated to the service may be necessary for some CDSM approaches. CDSM can be offered in a variety of approaches to participants.

Global Perspectives on Chronic Disease: prevention and Management Conference. Calgary, Alberta, Canada. October, 2007 (Peer reviewed paper presentation)

THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAMME WITH OR WITHOUT
SUPERVISED EXERCISE (CDSMP±EX). A QUALITATIVE STUDY OF PARTICIPANT
EXPERIENCE

Helen Cameron-Tucker, Menzies Research Institute and Faculty of Education, University of Tasmania and Royal Hobart Hospital, Tasmania. Christine Owen, Faculty of Education, University of Tasmania. Emily C. Hansen, Menzies Research Institute, University of Tasmania.

Acknowledgements: Physiotherapy Department Royal Hobart Hospital, Tasmania. University of Tasmania Australian Physiotherapy Research Foundation Beryl Haynes Memorial Fund. Royal Hobart Hospital Research Foundation Grant.

Purpose. We sought to understand experiences of people with chronic obstructive pulmonary disease (COPD) who attended the CDSMP±Ex at a metropolitan hospital instead of traditional cardiopulmonary rehabilitation, and so inform clinical practice.

Methodology. All study participants attended the CDSMP. Participants were also randomly allocated to supervised exercise or not. Semi-structured interviews were conducted with a purposeful sample of participants following the CDSMP±Ex. Data was subjected to iterative thematic analysis.

Results. Of the study sample of 68 participants, fourteen men and six women with severe COPD were interviewed over two years about their experience of COPD, CDSMP and supervised exercise. Major findings emerging from the data are presented. (1) The meaning of COPD was described in terms of its impact on participants' lives including physical symptoms, emotional response and loss. (2) Participants revealed self-developed strategies (planning and pacing, acceptance of limitations) for managing COPD. (3) Common social processes (influence of role models and social comparison) surrounding the CDSMP and supervised exercise provided motivation, and were as important as the exercise. In particular, participants indicated that action planning enhanced perceived personal control. (4) A choice of supervised exercise was overwhelmingly recommended with the CDSMP by participants. (5) Participants indicated a preference for the CDSMP instead of traditional approaches. (6) Participants revealed their meaning of self-management, noting self-reliance and self-consideration in particular. (7) The CDSMP and supervised exercise experiences emerged as participant-centred, in contrast to other healthcare encounters experienced by participants.

Conclusions. The impact of COPD is so profound it becomes its explanation. People bring self-management strategies to healthcare interactions. Common social processes act across the CDSMP and supervised exercise. Supervised exercise should be offered with the CDSMP for people with COPD. Participants prefer the CDSMP structure. Participants expanded upon literature definitions of self-management. A participant-centred healthcare approach is essential for healthcare interactions.

Thoracic Society of Australia and New Zealand (TSANZ) Annual Scientific Meeting: Auckland, New Zealand. March, 2007 (Peer reviewed poster presentation)

REASONS FOR NON-ATTENDANCE AT CARDIOPULMONARY REHABILITATION PROGRAMMES

Helen Cameron-Tucker^{1,4}, Lyn Joseph^{2,4}, Richard Wood-Baker^{3,4}

¹Departments of Physiotherapy, ² Nursing and ³Respiratory Medicine Royal Hobart Hospital, Hobart, Tasmania, 7001 and ⁴Cardiorespiratory Research Group, University of Tasmania, Hobart, Tasmania, 7001

Introduction: Of people with COPD referred to cardiopulmonary rehabilitation, not all enrol in the programme. Exploring contributions to this might assist in planning delivery systems to better address the needs of our patients.

Methods: We defined status: non-attendance (did not make/keep an appointment), non-enrolment (attending assessment only) and enrolment in our programme. Participants were referred from private specialists, hospital wards, hospital clinics, and other sources. Demographics, referral source and attendance were recorded. Chi-square analyses were used to determine relationships to variables.

Results: Over 21 months, 132 men (52.2%) and 121 women (47.8%) with an average age of 66.9 ± 11.8 years were referred. Of this group, 80 (31.8%) were non-attenders, 95 (37.7%) were non-enrollers and 77 (30.5%) enrolled. Age and gender did not significantly influence attendance, but referral source ($p=0.001$) and personal reasons ($p=0.001$) did. The proportion of non-attenders (14.3%) or non-enrollers (13.1%) was greatest for those referred from wards/clinics, while private specialists referred the largest proportion of enrollers (12.3%). Non-attenders versus non-enrollers were more likely not to be contactable (6.3% v 0.4%). Non-enrollers v non-attenders were more likely to have other commitments (8.7% v 6.0%), transport difficulties (5.6% v 2.4%), to have attended another programme

(4.0% v 1.2%) or to say the programme was 'unsuitable' (13.5% v 10.7%).

Conclusions: Referral source, suitability of service, attending to other commitments and transport difficulties contribute to whether or not people with COPD enrol in our rehabilitation programme. Exploring this further or developing alternatives to hospital group-based programmes may increase participation.

Support: Royal Hobart Hospital Research Foundation, Australian Physiotherapy Research Foundation Beryl Haines Memorial Fund.

Conflict of Interest: Nil

**Thoracic Society of Australia and New Zealand (TSANZ) Annual Scientific Meeting: Auckland,
New Zealand. March, 2007 (Peer reviewed poster presentation)**

**ACTION PLANS WITH PLANNED TELEPHONE FOLLOW-UP HELP SELF-MANAGEMENT
OF COPD: CASE PRESENTATION**

Helen Cameron-Tucker, Department of Physiotherapy, Royal Hobart Hospital and Cardiorespiratory Research Group, University of Tasmania, Hobart, Tasmania, 7001.

Introduction: Collaboratively defining goals, action planning and proactive telephone follow-up provide patient-centred care and incorporate self-management principles for people with COPD who do not wish to attend cardiopulmonary rehabilitation groups.

Methods: Baseline/ 3 months review included patient-defined goals, physical activity level, body-mass index (BMI), spirometry, dyspnoea (modified Medical Research Council, MMRC, scale), and six minute walk test (6MWT) with Borg 1-10 scale dyspnoea (SOB) and exertion (RPE) post walk. BODE index was calculated. A written action plan was collaboratively devised, telephone follow-up was mutually agreed, and time recorded and compared with usual appointments.

Results: The patient, a 66 year old man prescribed 3 l /min of supplemental oxygen, had an FEV1 of 0.5l (15% predicted). Physical activity was for self-care only. His goal was to increase fitness. Group attendance was declined as he disliked groups and structured exercise. His action plan of walking, 10 exercises for trunk, upper and lower limbs was incorporated into usual activities. Telephone follow-up was 1, 2, then 3 weeks apart. Four calls averaged 7 minutes (range 5-10 minutes), compared to 30 minute appointments. Action plan revision resulted in exercise repetitions increasing 5 to 10 times, walking 3 to 8 minutes. Frequency was twice daily. Baseline/ review BMI was 29.2/29.5, MRC 4/4, and 6MWT 310m, 1 stop limited by SOB=8 and 'burning quadriceps / 312m, 1 stop limited only by SOB=7. RPE was 7/6. BODE index was 7/7.

Conclusions: Setting an action plan facilitated self-management of regular physical activity. SOB, RPE and limitations to 6MWT decreased. Telephone follow-up provided guided feedback, revision of action planning and saves time. This approach may be useful for those people with COPD who cannot or who do not wish to attend a group programme.

Support: Nil

Conflict of Interest: Nil

Asia Pacific Society of Respirology Congress. Kyoto, Japan. November, 2006 (Peer reviewed poster presentation)

COPD: REHABILITATION AND THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAMME (CDSMP)

Helen Cameron-Tucker^{1,3}, Richard Wood-Baker^{2,3}

¹Departments of Physiotherapy, ²Respiratory Medicine Royal Hobart Hospital, Hobart, Tasmania, 7001 and ⁴Cardiorespiratory Research Group, University of Tasmania, Hobart, Tasmania, 7001

Background: Self-management programmes are considered integral for optimal care of people with chronic conditions. Unlike traditional cardiopulmonary rehabilitation (CPRP), CDSMP facilitates development of self-management skills and self-efficacy (belief in ability to achieve goals), a suggested mechanism for sustained health-behaviour change. Also unlike CPRP, supervised exercise is not included in CDSMP.

Method: A pilot of CDSMP was conducted at an Australian tertiary hospital in 2003, to compare with CPRP offered previously. Physical capacity, measured by six minute walk distance (6MWD) pre and post CDSMP, was compared with CPRP. Health status and behaviours were evaluated (CDSMP) by self-administered questionnaires.

Results: Of 24 bookings for CPRP, 14 participants attended the post-programme data collection. Of 28 bookings for CDSMP 12 people attended the post-programme data collection. Attrition was predominantly due to exacerbation of COPD or co-morbidities. The mean \pm SD change in 6MWD was 30 ± 54 m for CDSMP and 9 ± 87 m for CPRP. There was no significant difference between pre- and post-programme 6MWD for either CPRP or CDSMP, nor between the different programmes ($p = 0.49$).

CDSMP significantly improved mean cognitive symptom management (pre = 2.2 ± 0.9 , post = 2.6 ± 0.8 , $p = 0.05$). There were changes for shortness of breath measured by a visual numeric (pre = 6.5 ± 2.8 , post = 5.7 ± 2.1), median self-reported walking (pre = 15 minutes, range 0-180 minutes; median post = 120 minutes, range 15-180 minutes), mean self-efficacy (pre = 6.4 ± 2.0 , post = 7.0 ± 2.0), and depression measured by the Kessler-10 questionnaire (total score pre = 19.8 ± 7.6 , post = 18.1 ± 6.1). None of these reached statistical significance.

Conclusions: The data suggests that people with COPD obtain small benefits from CDSMP and that average physical capacity improves despite the absence of supervised exercise.

New Perspectives Conference. Victoria, British Columbia, Canada. September, 2005 (Peer reviewed paper presentation)

IMPLEMENTATION AND OUTCOMES OF THE STANFORD CHRONIC DISEASE SELF-MANAGEMENT PROGRAMME (CDSMP) INSTEAD OF REHABILITATION *PROGRAMMES* AT AN AUSTRALIAN CAPITAL CITY HOSPITAL.

Helen Cameron-Tucker, Department of Physiotherapy, Royal Hobart Hospital, GPO Box 1061L, Hobart 7001, Tasmania, Australia. cameronh@utas.edu.au PHONE: 61-3-6222 8571 FAX: 61-3-622 7534

Rationale: Cardiopulmonary and cardiac rehabilitation programmes at a city hospital provided similar information, resulting in duplication. With increasing patient numbers, an alternative model was sought.

Objectives: In 2004, the Stanford CDSMP replaced both traditional rehabilitation programmes. Completion rates, outcomes pre- and post- programme and participant feedback were evaluated.

Method: Eighteen multidisciplinary health professionals were trained as CDSMP leaders. Attendance records were kept. Health status, health behaviour and participant satisfaction was evaluated over 6 months by self-administered questionnaires.

Results: Of 82 bookings, there were 16 non-starters, 37 attended 4 or more sessions and 29 attended 1 to 3 sessions. There were 66 pre-programme evaluations. Comparisons were made with 21 complete pre and post-programme data sets. There was insufficient 6 month data. A significant improvement was demonstrated in cognitive symptom management ($p=0.006$), with small positive but not significant trends noted in shortness of breath, depression and self-efficacy for managing chronic conditions. Pain, general health, fatigue and stretching and strengthening exercises did not change. Aerobic exercise decreased. Patient feedback indicated both a preference to 'have more like me' in the group and queries re the absence of supervised exercise. Due to departmental structures and in response to patient feedback, a decision was made to offer the CDSMP to condition- specific groups from 2005.

Conclusions: The CDSMP has been embraced by management and staff. Although a small convenience sample, positive trends in outcomes were demonstrated. A randomised controlled trial of the CDSMP with or without supervised exercise has commenced.

Heart Failure Forum. Canberra, Australia. June, 2004 (Peer reviewed paper presentation)**A PILOT TRIAL OF THE STANFORD CHRONIC DISEASE SELF-MANAGEMENT PROGRAMME FOR PATIENTS WITH CARDIOVASCULAR, CARDIOPULMONARY AND DIABETIC CONDITIONS AT THE ROYAL HOBART HOSPITAL**

Helen Cameron-Tucker, Physiotherapist, Royal Hobart Hospital, Liverpool Street, Hobart, Tasmania. 7005. (03)62228571 helen.camerontucker@dhhs.tas.gov.au

A pilot trial of the Stanford Chronic Disease Self-Management Programme(CDSMP) is being conducted at the Royal Hobart Hospital (RHH). At the RHH patient education programmes for people with cardiovascular, cardiopulmonary and diabetic conditions, three of the Australian Government's National Health Priority Areas, have traditionally been delivered as condition-specific models and incorporate the SNAP framework of smoking, alcohol, nutrition and physical activity. By providing similar information across three separate patient groups, duplication of staff services occurs. Attempts at providing a combined programme for patients with heart failure and chronic respiratory conditions, such as COPD, have been made previously (Heart Lung Management Programme, HLMP). This experience will be discussed.

Fostering sustainability of behaviour change is a challenge facing health professionals. Traditional patient education approaches have resulted in improved outcome measures but sustainability was unclear. One of the Stanford patient self-management programmes has been shown to sustain benefits up to four years, involves two leaders and has generalisability across chronic conditions. This is a programme wherein patients are recognised as partners in health care. With this in mind, it was decided to trial the CDSMP at the RHH. A rationale for this decision, initial outcomes and early lessons will be presented.

D.2 Related Professional Development

2002: Leader Training, Stanford Chronic Disease Self-Management Programme

2002: Flinders Chronic Disease Management Training

2003: Motivational Interviewing Training

2004: Workplace Evaluation and Training Certificate Level IV

2004: Master Trainer, Stanford Chronic Disease Self-Management Programme

2005: Health Coaching Training

2006: 'CoMment' Mentor Training

2008: 'The Aussie Heart Guide', Heart Manual Training, Professor R. Lewin,
University of York, UK.

Appendix E: A Resource Booklet for Healthcare Providers

**THE ‘CENTREd FRAMEWORK:
STRATEGIES AND TOOLS
FOR PARTICIPANT-CENTRED ENGAGEMENT
FOR HEALTHCARE (PCEH)**

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E.1 Introduction

This booklet is designed to assist health professionals reading this thesis who might ask for description of essential skills they require and how the elements of the Participant-CENTREd Engagement for Healthcare framework could be applied to clinical practice. In my study, it was being considered in a holistic sense that emerged as a crucial element in the predominantly positive experiences of the supervised exercise sessions and the CDSMP for participants with COPD. That is, participants indicated they felt they were considered as a person with preferences, ideas, expectations, skills and concerns, and were recognised and respected as someone who could work in partnership with health professionals to exert personal control over their life with a chronic condition. The common thread of the CDSMP and the supervised exercise sessions was a participant-centred engagement between participant and health professional.

The CENTREd Framework has implications for professional practice; and because of its potency, it is discussed in some detail in this booklet, with reference to my research. Finally, it is essential that this framework be tested in clinical practice. Suggested outcomes and measures are referred to and an evaluation tool presented.

The following pages contain:

- Definitions of participant-centred healthcare, self-management and self-management support
- The CENTREd Model and its elements
- The CENTREd Framework: Skills, Strategies and Outcomes
- The CENTREd Framework Flow-chart
- Applying the CENTREd Framework

E.2 Definitions

Participant-centred healthcare is a holistic concept, representing a partnership between the person with the condition, their family or carers and the healthcare provider, based on mutual trust, respect, empathy and good communication, directed towards informed shared decision-making and provision of tools to address mutually agreed goals that focus on the main concerns and needs of the individual (Battersby et al. 2003; Coulter 2002; Gerteis 1993; Rodriguez et al. 2008; Shoor & Lorig 2002; Towle & Godolphin 1999; Tuckett et al. 1985; Von Korff et al. 1997).

Self-management is a dynamic process incorporating an individual’s capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-tailoring context to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains. In order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities. Fulfilling responsibilities requires the undertaking of specific activities, acknowledged in the literature (Battersby et al. 2003; Clark et al. 1991; Corbin & Strauss 1988; Kralik et al. 2004; Lorig 2003) and expanded upon in my thesis (Table 1).

Table 42: Expanded Self-Management Responsibilities and Activities

SELF-MANAGEMENT RESPONSIBILITIES	SELF-MANAGEMENT ACTIVITIES
<i>Respond to the impact of a chronic condition on one’s overall health, incorporating a sense of self and the physical, mental, social, emotional and spiritual aspects of health</i>	<i>Having awareness of thoughts pertaining to the self (self-reliance, self-awareness, acceptance), and prioritising, planning and pacing to maintain roles in life</i>
<i>Monitor and respond to the symptoms of the chronic condition</i>	<i>Following a symptom-related action plan which requires knowledge of the condition and its symptoms, the skill to monitor and interpret them, and to follow an agreed plan of action. In this way the person self-regulates</i>
<i>Engage in behaviours to promote good health</i>	<i>Having an understanding of health-related behaviours and how these relate to individual circumstances. Adopting behaviours in a self-tailoring context</i>
<i>Utilise resources, both internal (personal) and external (various sources)</i>	<i>Seeking and implementing information concerning health in general and in health-related behaviours</i>
<i>Work in partnership with healthcare providers and carers</i>	<i>Communication and decision-making skills to effectively work with carers and healthcare providers</i>
<i>Learn core self-management skills</i>	<i>Setting goals with action plans to achieve those goals</i> <i>Problem-solving skills (problem identification, seek, implement and evaluate possible solutions)</i>

Self-management support refers to the assistance people are given to manage the often variable impact of chronic condition(s) on their lives, in terms of personal skills, medical and social assistance (Bodenheimer, Wagner & Grumbach 2002) and personal feedback about their health and behaviour change (McMurray 2002).

Participant-centred engagement for healthcare (PCEH) is suggested as one way of engaging with and supporting people who seek to manage their health. That is to say, PCEH provides self-management support in a participant-centred framework. It occurs along a continuum of acuity to severity.

E.3 The 'CENTREd' Model is shown in Figure 18 (repeated here for reference) and its proposed elements are defined below.

Commitment

Commitment to the ideal of a 'partnership', based on mutual respect, empathy and trust between participants and health professionals is fundamental to the philosophy of participant-centred engagement. The partnership considers the psychosocial, cultural and educational background of participants, their family, significant others or carers.

Engagement

The partnership engages in, explores and respects the participant's preferences, ideas, feelings and expectations; acknowledges the mutual expertise of both health professional and participant and recognises his/her motivational level.

Negotiation

The partnership affirms positive actions, defines areas of mutual concern, engages in negotiation of goals and action planning to address these concerns, ensuring the provision of relevant information and skills to arrive at informed shared decisions.

Taking action

Specific action plans are set to address areas of mutual concern.

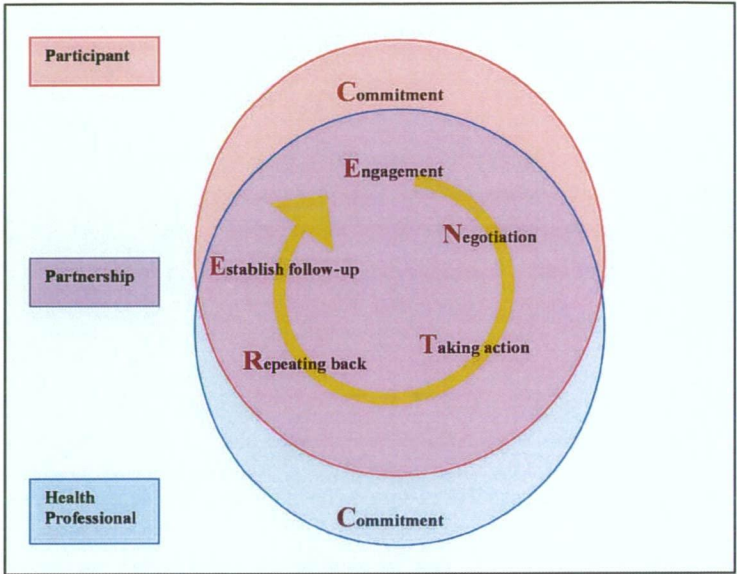
Repeating back

Both participant and health professional repeat back relevant information to ensure understanding and provide clarification where necessary.

Establishing follow-up

The partnership mutually establishes and agrees to planned follow-up.

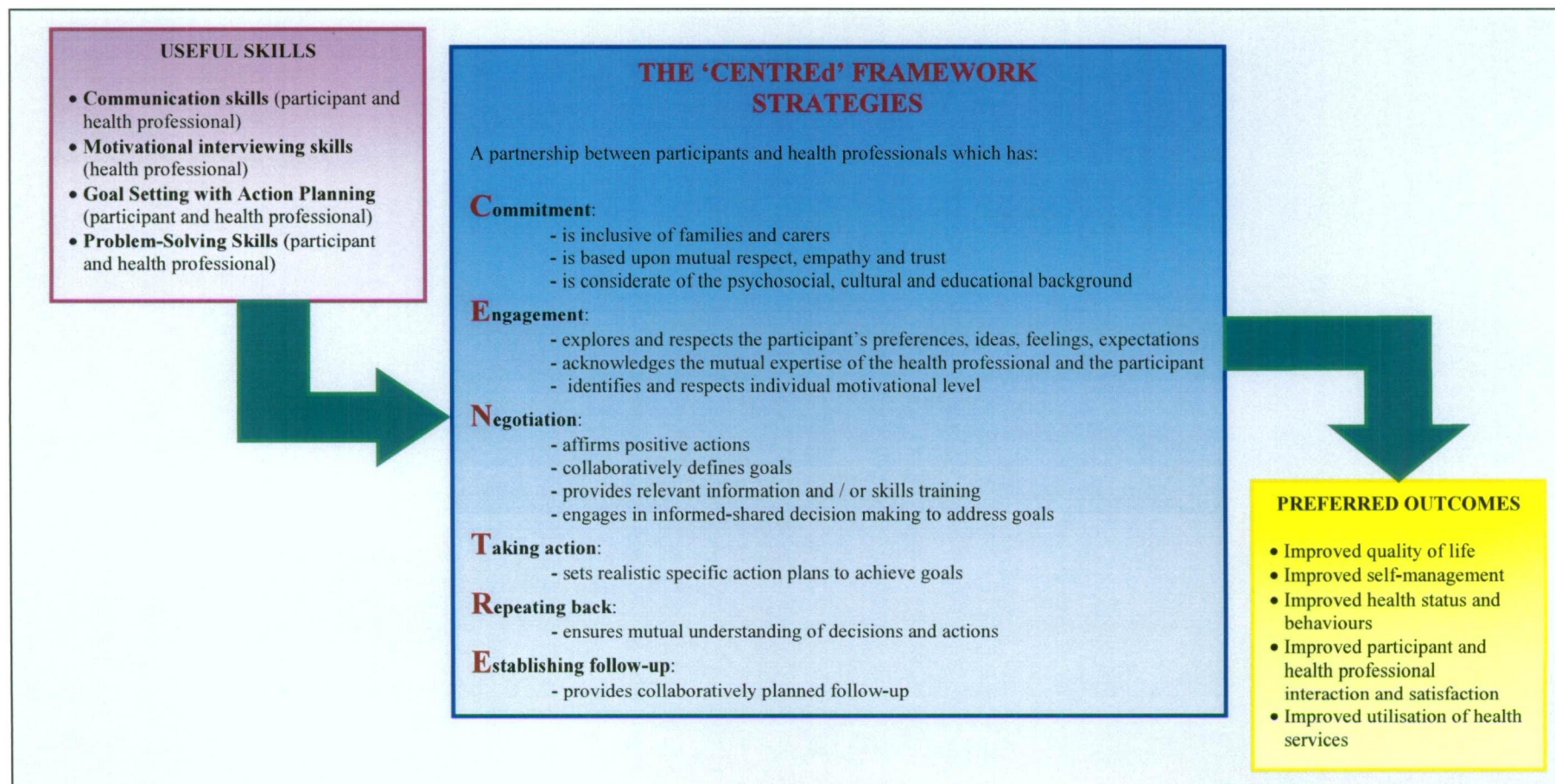
Figure 18: Model for Participant-CENTRED Engagement for Healthcare



E.4 The ‘CENTRED’ Framework: Skills, strategies and outcomes

The ‘CENTRED Framework’ shows skills, strategies and outcomes (Figure19, repeated here for reference). The flow of interaction is shown in Figure 22. An example of how the CENTRED Framework for PCEH may be applied in a clinical interaction is depicted in Table 47 later in this chapter. What might be considered core tools and skills for PCEH are discussed below.

Figure 19: Participant-CENTREd Engagement: Skills, Strategies and Outcomes



E4.1 ‘CENTREd’ Framework Tools and Skills

Communication is integral to any interaction and communication skills training is fundamental for participant-centred consultations (Siriwardena et al. 2006). Communication skills encompass

- non-verbal communication,
- verbal communication and
- listening.

They improve the healthcare professional’s ability to display empathy, reassurance and acknowledgement of participants’ efforts (Brown et al. 1999) that aid in establishing rapport. Good communication aids in

- identifying the participant’s main problems from his/her perspective,
- in exploring needs and preferences, and
- in understanding the context and impact of the participant’s condition on his/her life (Little et al. 2001).

It is beyond the scope of this booklet to provide detail concerning communication skills training. Counselling texts contain a wealth of information about communication skills training, including a recently published text for health professionals (Burnard 2005). However, some specific skills from clinical practice are explained below. They include:

- Specific communication skills (participant and health professional)
- Motivational interviewing skills (health professional)
- Problem-solving skills (participant and health professional)
- Goal setting with action planning (participant and health professional)

E4.1.1 Specific Communication Skills

Open-ended questions

A useful verbal communication skill is the use of open-ended questions which support an invitational style of interacting. Questions commencing with ‘*Tell me.....*’ do not direct the answer but invite individuals to answer from their perspective. They enable health professionals to gain some understanding of areas of concern for that person, to prioritise and to set an ‘agenda’ for the interaction (Rodriguez et al. 2008). Open-ended questions are one of the skills used in motivational interviewing described later. Examples of open-ended questions are shown in Table 43.

‘I’ Statements

The use of ‘I’ statements is a useful tool which can be used to identify the issue, to articulate an emotional response and preferred outcome (Launceston City Council 2003). An example of how this may be used is shown in Table 43 below.

The use of ‘I’ statements is especially useful if a person is experiencing difficulty in articulating areas of concern they wish to have addressed. The health professional may respond with a statement which seeks to clarify and acknowledge the concern, inviting discussion of previous attempts to address the issue before discussing the preferred outcome. By framing concerns in this way, the participant is guided to understanding that they have named a goal (in the above example, making stair climbing less stressful). From this an action plan to achieve the goal may be developed. Setting Action Plans will be elaborated upon later in this booklet.

Table 43: Communication Skills: Application of ‘I’ Statements

Participant: ‘I’ Statement	Example of Application
Emotional response: <i>‘I feel...’</i>	Emotional response: <i>‘I feel really embarrassed and useless,’</i>
Statement/Reason: <i>‘because I...’</i>	Statement/Reason: <i>‘because I am gasping by the time I reach the top of the stairs.’</i>
Preferred outcome: <i>‘I would like....’</i>	Preferred outcome: <i>‘I would like to manage the stairs without feeling so useless.’</i>
Health Professional: Participant-Centred Engagement	Example of Application
Acknowledgement: Acknowledge participant’s concerns and feelings.	Acknowledgement: <i>‘I understand from what you have told me that this is difficult for you.’</i>
Statement: Identify area of concern. Seek clarification.	Statement: <i>‘You are talking about a concern with climbing the stairs.’</i> Seeking clarification: <i>‘Have I got that right?’</i>
Preferred outcome: Confirm previous efforts. Invite collaboration.	Preferred outcome: <i>‘Tell me what you have tried [to make stair climbing less stressful]’</i> <i>‘Let’s see if we can work out a way around this.’</i>

Adapted from LCC, Launceston City Council (2003) ‘ComMent Trainers Manual’

Listening

Fundamental to a discussion is listening. Health professionals benefit by listening not just to the words people use, but to the message people are conveying. Others have described listening and interpreting as a core clinical skill (Greenhalgh & Hurwitz 1999). By listening attentively, without interruption and allowing people to describe what matters to them, the health professional will gain much knowledge of the person, their concerns and their motivational orientation. Reflective listening is one of motivational interviewing skills, described next.

E4.1.2 Motivational Interviewing Skills

These skills are drawn from the work of Miller and Rollnick, and the reader is referred to these publications for more detail.(Miller & Rollnick 1991; Miller & Rollnick 2002; Rollnick & Miller 1995).Motivational interviewing is

- a participant-centred, goal-directed style of interaction
- aimed at increasing internal motivation to change behaviours
- by creating awareness of and encouraging exploration of ambivalence (Rollnick & Miller 1995).

The ‘CENTRED’ Framework does not presume to use the style of ‘motivational interviewing’. Indeed it differs from motivational interviewing in that ‘direction’ is suggested to the participant through a ‘menu’ of health behaviours (Table 46). However, the participant-centred spirit of motivational interviewing resides in the framework, recognising that ultimately it is the person who decides his/her behaviour. The CENTRED Framework draws upon motivational interviewing skills. These are:

- Open-ended questions: invite description and explanation from the participant’s perspective
- Affirmation: praise, acknowledging, appreciation of positive actions
- Reflective listening: displays empathy for the person’s feeling, meaning, frame of reference
- Summarise: repeat back, seek clarification, link discussion points

This style of interaction creates awareness of the current situation and ascertains where people are situated on an intention-decision continuum. Useful tools used in motivational interviewing when facilitating behaviour are

- the ‘behavioural ruler’ and
- envisaging possible futures.

‘Behavioural Ruler’

The ‘behavioural ruler’ is a useful tool that may be used in conjunction with this style of interaction. The ‘behavioural ruler’, adapted for this thesis from the ‘confidence’ and ‘importance’ rulers described by (Miller & Rollnick 2002) is shown in Figure 20 below.

Figure 20: 'Behavioural Ruler'

Behavioural Ruler										
Mark on a scale of 0 -10, where you are now with respect to doing [the behaviour]. Zero equals 'not undertaking the behaviour', and 10 'undertaking the behaviour according to recommendations'.										
0	1	2	3	4	5	6	7	8	9	10
Zero = Not undertaking the behaviour						10 = Undertaking the behaviour				
<p>Example:</p> <p>Where on this scale are you with respect to doing [exercise]? '0' equals not doing [any exercise] and '10' equals [doing moderate exercise for 30 minutes on at least five days of the week].</p> <p>Why are you marking a [lower number]? Tell me what it would take for you to mark a [higher number]? How important is it for you to reach the [higher number]? How confident are you that you can reach the [higher number]? What would you like to do about that?</p>										

Adapted from Miller and Rollnick (2002) *Motivational Interviewing: Preparing people for change*. Guilford Press. New York

The 10-point 'behaviour ruler' is anchored at either end by zero and 10, with zero equating to 'not undertaking the behaviour', and 10 'undertaking the behaviour according to recommendations'. The participant is asked to circle the number which equates to the behaviour they are doing now. He/she is then asked why they are at this level and not a lower level, followed by a query as to what they would have to do to move to a higher level. With this approach, participants focus on what they *are* doing, which can become a basis for further behaviour adoption.

Envisaging Possible Futures

Participants may be encouraged to envisage a possible future by asking, '*What will happen if you do this/do not do this/stay the same?*' Under the style of motivational interviewing, this questioning serves to create ambivalence in the participant about their behaviour.

Looking Back

Individuals may also be encouraged to '*look back*' at what they were doing in the past, as a way of identifying goals they may wish to work towards, by asking questions such as, '*What are some of the things you used to do that you would like to do again?*' However, there is a note of caution. For people who become progressively limited in their abilities due to their condition, 'looking back' may serve to reinforce the decline in physical capacity. For example, for some people with COPD, not being able to do the 'things' they wanted to do because of breathlessness and physical limitations was a major source of frustration. Recalling what they 'used to do', served to reinforce the decline in physical capacity. In this situation, it may be more helpful to focus on what people currently do to manage their

lives with a long term condition. This serves to positively reinforce behaviour and enable its progression or maintenance. The ‘behavioural ruler’ assists in this regard.

E4.1.3 Goal Setting and Action Planning

Defining goals and setting action plans are fundamental self-management activities addressed in different models of self-management education (Battersby et al. 2002; Kelly, Menzies & Taylor 2003; Lorig, Sobel et al. 1999), drawing upon the work of others (Bandura 1986, 1997; Clark, Gong & Kaciroti 2001; Schwarzer 2001). Goals give direction to the behaviour and describe *what* is planned. Action plans provide the details of *how* the goal is to be achieved. Specific properties of goals and action plans are shown in Tables 44 and 45.

Table 44: Goals and Action Plans

The Goal: <i>what</i> the person is aiming to achieve	
Goal Proximity	<p>Distal or Overall goals</p> <ul style="list-style-type: none">• Give direction to where we are heading.• May be ‘too big’ to achieve all at once.• May be ‘general’ and not behaviour-specific. <p>Proximal or sub goals</p> <ul style="list-style-type: none">• Break overall goals into ‘achievable’ units.• Influencing current behaviour.
Goal Specificity	<p>Clear specific personally relevant goals provide</p> <ul style="list-style-type: none">• a framework for evaluation of progress.• intrinsic motivation to self-regulate behaviour.
Goal Level	<p>How high or low to ‘set the bar’ for the goal:</p> <ul style="list-style-type: none">• Too high: strong effort with repeated failure weakens self-efficacy and motivation.• Too low: achieving goals with minimum effort does not build strong self-efficacy to persevere against barriers.
The Action Plan: <i>how</i> it is going to be achieved	
Action Planning	<p>Action plans</p> <ul style="list-style-type: none">• are directed towards achieving the goal or sub-goals.• aid in developing confidence to undertake activities• enable progress to be monitored.• are personally relevant.

‘SMARTIC’ Action Plans

The ‘SMART’ acronym (author unknown) is often used as a framework when setting action plans. This is extended to ‘SMARTIC’ in this booklet, to capture ‘importance’ and ‘confidence’ (Table 45).

Table 45: An Example of Using the ‘SMARTIC’ Action Plan

‘SMARTIC’	Suggested Questions	Example of Setting an Action Plan
Specific The action plan addresses a specific behaviour related to the goal.	What do you want to do? Tell me exactly what you will do to get fitter?	<i>‘Get fitter and healthier.’</i> <i>‘Walk. Eventually I want to achieve 30 minutes of walking on at least five days of the week.’</i>
Measurable The behaviour needs to be measurable, to enable progress to be gauged. It defines: <u>How often</u> : frequency per day, frequency per week? <u>How much</u> : duration, cost, size, amount? <u>When</u> : for example, time of day?	When [during the day] are you going to do this? How often are you going to do this? How much / how long / how many are you doing?	<i>‘Mid afternoon, around 2.00pm.’</i> <i>‘At first, three times per week, on Monday, Wednesday and Friday.’</i> <i>‘I will walk for 10 minutes, have a rest, and walk for another 10 minutes. So I will walk for 20 minutes in total.’</i>
Attainable The plan should be challenging, realistically achievable and address an action.	Make sure the plan is one you can reasonably expect to achieve. Make sure it is an action-based plan.	<i>‘If I have a rest I know I will be able to achieve the 20 minutes. I can build up from this.’</i>
Relevant The plan needs to be one the person wants to do.	Make sure the plan is something YOU choose to do.	<i>‘I really want to be fitter and healthier. Then it will be easier to climb the stairs and maybe I will not become unwell so often.’</i>
Time-frame The plan should have a defined time by which it is to be achieved. These should be proximal timeframes, with the overall goal achievable in the foreseeable future.	Let’s set a time to have this goal and plan(s) completed.	<i>‘I will increase the days I walk then the time. I will give myself two months to be able to achieve 30 minutes of walking on at least five days of the week.’</i>
Importance Self-rate on a scale of zero to 10.	How important is this plan to you? Zero is not important at all, and 10 is as important as it could be.	<i>‘This is 9 out of 10 important to me.’</i>
Confidence Self-rate on a scale of zero to 10.	How confident are you that you can complete this plan? Zero is not confident at all, and 10 is as confident as you could be.	<i>‘I am 7 out of 10 confident I can do this.’</i>
Importance and Confidence Rulers if the interaction is face-to-face.		
<div><div>012345678910</div><div>Not importantImportant</div></div>		
<div><div>012345678910</div><div>Not confidentConfident</div></div>		

By focusing on what a person can and wants to do, intrinsic motivation is enhanced. However, this is not to say that condition-specific health-behaviours are not addressed, as noted below.

E4.1.4 A ‘Menu’ of Health Behaviours: SNAPPS

A ‘menu’ of behaviours referring to condition-specific behaviours or to behaviours for general health is a useful tool to gauge what health behaviours a person is engaging in, and may be presented to participants, from which choice is exercised. The acronym ‘SNAPPS’, adapted from other publications (Department of Health and Human Services 2005; Joint Advisory Group on General Practice and Population Health 2001; Royal Australian College of General Practitioners 2004) provides a useful health behaviour ‘menu’ (Table 46). Nevertheless, if directly choosing health behaviours is not their preference, then it is the skill of the health professional to link the participant’s preferred goals to health behaviours, with approaches such as, ‘*Let’s look at what you will need to do to be able to go on holiday with your family*’. This then paves the way to address a ‘menu’ of health behaviours (Table 46) for the condition or for general health may be suggested to participants, from which choice is exercised.

Table 46: ‘SNAPPS’ Health Behaviours Menu

HEALTH BEHAVIOUR	HEALTH BEHAVIOUR GUIDELINES
Smoking	STOP smoking. Avoid passive smoking. Avoid smoke-filled atmosphere.
Nutrition	Eat a balanced diet with a wide variety of foods. Eat 5 serves vegetables and 2 serves of fruit a day. Eat plenty of wholegrain bread, pasta, rice. Eat lean meat, poultry and fish. Have oily fish three times a week. Eat low fat dairy products. Limit fat, salt and sugar. Drink plenty of water. Monitor weight.
Alcohol	Drink alcohol in moderation: <ul style="list-style-type: none">no more than two standard drinks on any day for men and womenno more than four standard drinks at any one time for men and womenhave at least two alcohol free days a week.no drinking for children and adolescents under 15 years of agedelay drinking for 15 – 17 year old young people for as long as possible,
Physical activity	Accumulate at least 30 minutes a day of moderate exercise on all or at least five days of the week.
Psychosocial	Manage emotions and seek help if needed. Be aware of self-talk. Maintain or develop social networks.
Symptom management	Monitor and interpret symptoms. Take medications regularly. Follow an agreed plan of action. Have regular review.

Adapted from: (1) Department of Health and Human Services (2005) Strengthening the Prevention and Management of Chronic Conditions. Policy Framework. Tasmanian Government, DHHS. Hobart.

(2) RACGP, Royal Australian College of General Practitioners (2004) SNAP: a population health guide to behavioural risk factors in general practice. RACGP. South Melbourne

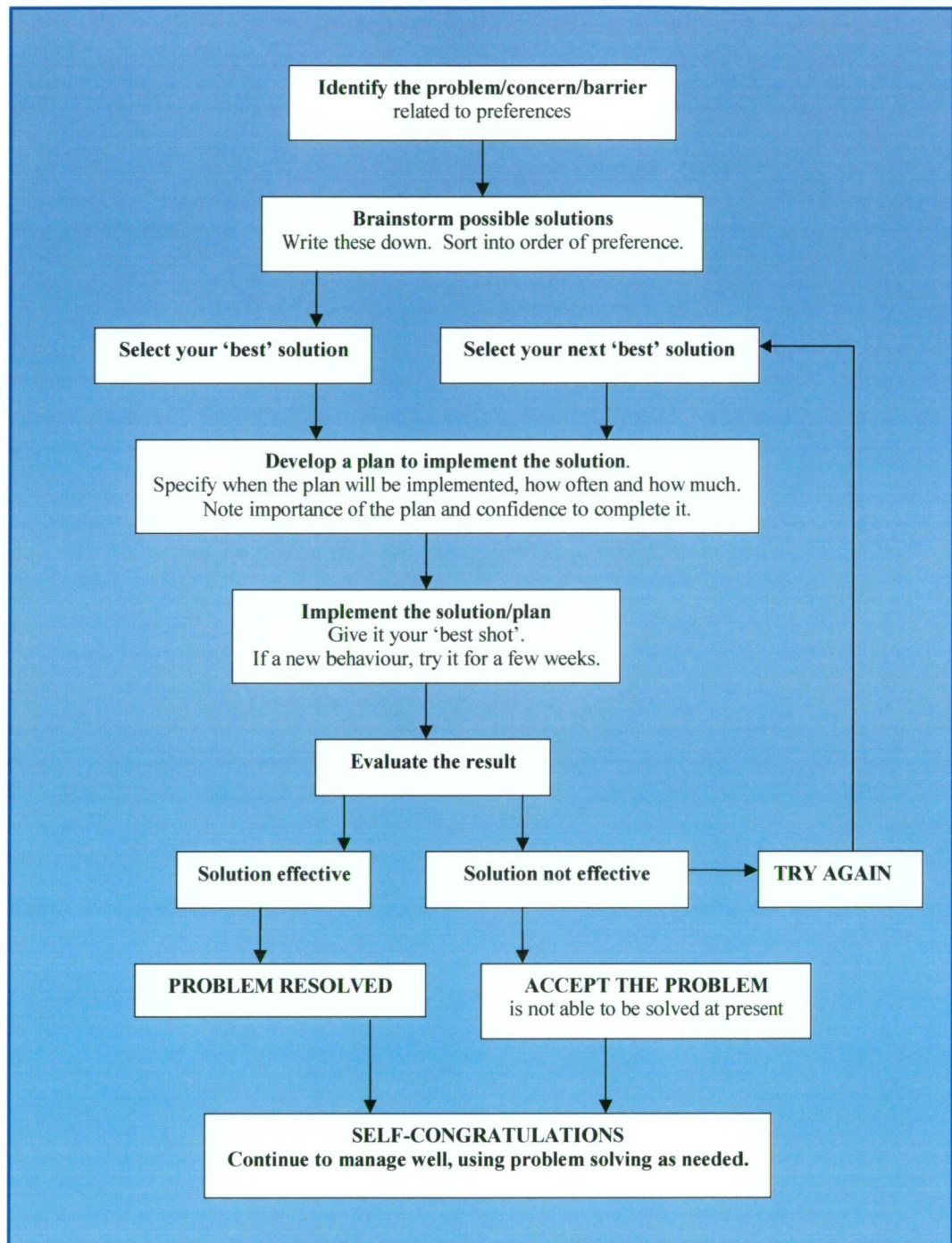
E4.1.5 Problem Solving Skills

If participants refer to barriers to behaviours, problem solving skills are useful to identify possible solutions. The problem-solving steps are shown in Figure 21. Problem-solving skills are fundamental to managing any difficulty in life. However, people with chronic conditions may face a plethora of difficulties. As such, problem-solving skills assume great importance. Identification of the problem is the first and often most difficult step for an individual to undertake in this process. It may be useful to ask *'What is getting in the way of my / your [walking to the corner each afternoon]?' or, 'What happened to stop me/you from [using my exercise bike today]?'*

Steps for problem solving are described in the CDSMP (Lorig, Gonzalez & Laurent 1999). Others have reported a similar process for self-evaluation of problems and implementing solutions, aimed at helping people to address negative thought processes (Bowman, Scogin & Lyrene 1995; Warmerdam, van Straten & Cuijpers 2007). The problem-solving steps in Figure 21 are adapted from these sources.

Once the problem has been identified, the individual is in a position to consider possible solutions. This can be considered by oneself or in conjunction with the health professional. With a list of suggestions for solving the problem generated, a possible solution may be implemented in a similar manner to setting an action plan. The process of selecting and trying a possible solution if there is no problem resolution may be repeated, or a decision made that the problem may not be solvable now.

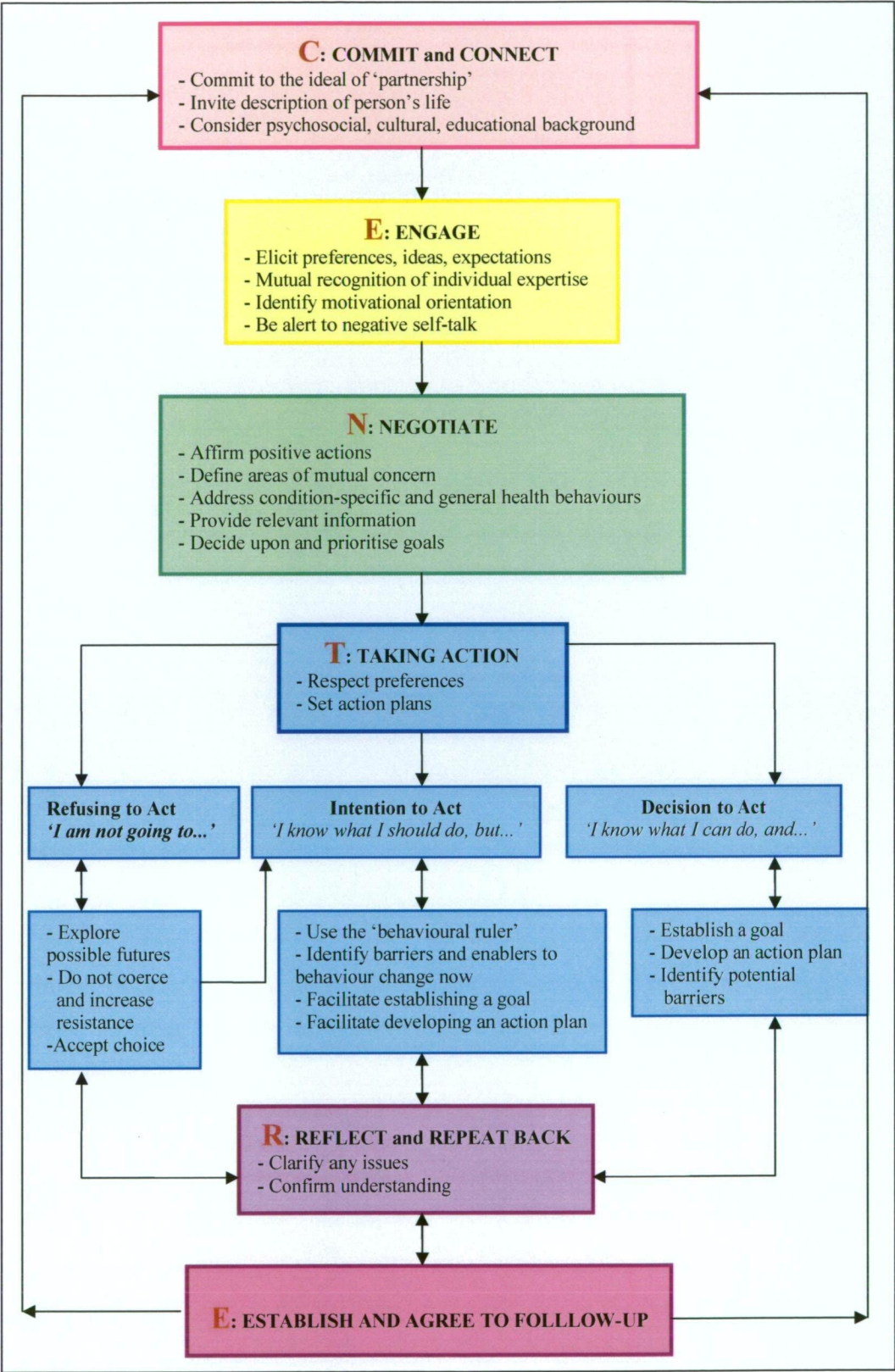
Figure 21: Problem Solving Steps



E4.2 'CENTRED Framework Strategies and Elements

The elements of the CENTRED framework are discussed in further detail below, bringing together the strategies, skills and tools which might be employed during participant-centred healthcare interactions. Figure 22 depicts a flow of interaction, recognising that this is an iterative process and may result in movement between elements. In addition, the depth of interaction will be determined by the acuity or chronicity of the condition

Figure 22: The ‘CENTREd’ Framework Flowchart



The elements of the CENTREd framework are discussed in further detail below. Table 47 provides an example of how these elements might be applied in clinical practice.

E4.2.1 Commitment

The ideal of partnership (Figures 18 and 19, repeated in this booklet) has been advocated by others (Shoor & Lorig 2002; Von Korff et al. 1997), inclusive of family and carers (Clark, Gong & Kaciroti 2001). The acknowledgment of significant others in the management of chronic disease points to the wider social context of the healthcare system and the community within which it is situated, implicating systems of healthcare delivery, support, decision-making, and clinical information (Wagner et al. 1999). A partnership should include participants and families at this systems level, particularly with respect to access to care, design and coordination of care and ultimately policy (Bergeson & Dean 2006). Chronic disease management points to management of health in general and prevention of disease in the first place. This implicates population health and environmental planning initiatives, which should seek input from individuals within the population by establishing partnerships with consumer groups.

Respect and empathy are shown by the way in which the participant and health professional engage during the interaction. By enquiring as to the illness experience, listening to the person's viewpoint and valuing their input, an understanding of the domains of life over which the person perceives they have control, as well as areas of concern, may be gleaned. By trying to place themselves in the milieu of a person's life, health professionals move towards an empathetic interaction.

Trust is a pillar of a participant-centred engagement. People with health conditions should be able to trust that their healthcare professionals will provide unbiased information based on the best available evidence and that benefits and risks of management will be openly discussed (Coulter 2002; Elwyn 2006). They should be able to trust that they will be treated in a courteous, sympathetic and respectful way, and their perspective valued. There should be implicit trust that confidentiality will be maintained at all times, and permission sought to disseminate personal information. Interactions failing in this regard may result in formal complaints and litigation (Coulter 2002). In addition, they should be able to trust that the service they receive will be reliable and as expected (Walker 2003).

Health professionals should be able to trust participants to engage openly and honestly, that is, to take what they are told at face value without suspecting a hidden agenda. However, because of the potential for some participants to be reticent to disclose very personal information or that which they fear may invite censure, health professionals may need to state openly that they will trust 'what you tell me' and that they are not there to judge but to assist. Putting the person at ease, conveying empathy and concern, facilitating a dialogue and actively listening are ways of enabling open communication.

Evaluating commitment

Specific questions may be asked of participants as to their experience of the interaction with their healthcare provider (Coulter 2002) and health professionals may reflect upon their practice, self-reporting on the same questions.

There are a number of tools evaluating interpersonal dimensions of a consultation reported in the general medical practice literature (Looi 2008; Mercer & Howie 2006; Ramsay et al. 2000). Mercer and Howie (2006) have integrated measures of interpersonal effectiveness from previously validated tools into one newly validated instrument, the consultation quality index version two (CQI-2) that measures four elements: empathy; enablement (how the consultation has aided an understanding of and coping with health concerns); continuity of care (how well the consulting doctor is known to the participants) and consultation length (the actual time spent in consultation with the doctor). Participants also report their overall satisfaction and confidence in their doctor. While this tool was trialled in general practice, it could be applied to interactions with other health disciplines.

Questions relating to trust, inclusion of significant others, whether there was a sense of working together—in a partnership—or whether this was valued were not included in the above tools and could be addressed in future assessments. Enquiry as to the value and importance of a partnership and whether it was perceived to have occurred would be necessary if commitment is to be gauged.

Commitment with its elements of respect, empathy and trust need to be interwoven throughout the whole interaction. People come to the interaction with these elements, which influence and result from the ensuing engagement.

E4.2.2 Engagement

Engaging with and eliciting the participant's preferences, ideas, feelings and expectations (Figure 22) has been described as a priority for healthcare by others (Towle & Godolphin 1999), and is recognised as a health professional skill that affords as complete information as possible about the main concerns and priorities from the participant viewpoint (Rodriguez et al. 2008). These may be quite different to those defined by the health professional. As the qualitative findings of my study revealed, being asked what was of most importance to them, was a major differentiating factor of both the CDSMP and supervised exercise when compared with more traditional interventions. With participant permission, families and carers should be invited to share their concerns and preferences. This is essential in the case of younger children or for those who cannot advocate for themselves.

Knowing about participant and family preferences is important when considering interventions. For example, in my study, nearly one-quarter (22.1%) of those referred declined an initial appointment because of programme unsuitability. Knowledge of interaction preferences enables offering a suite of alternatives such as individual face-to-face consultation, telephone-mentoring or discourse via email, to name a few.

Acknowledging the mutual expertise of the participant, carers and the health professional (Tuckett et al. 1985) moves the relationship from health professional as *expert* to health professional as *partner*, and participant from a *passive* to an *active* role in the partnership. Individuals should respect that health professionals are best situated to diagnose and offer care based on the best available evidence, just as health professionals should respect that participants and their carers best know the impact of a condition such as COPD on their lives (Coulter 2002). Recognising the self-developed self-management strategies people with chronic disease bring with them to healthcare interactions emerged from my study as an important consideration.

Identifying and respecting an individual's motivational level is essential if behaviours are to be adopted or maintained. For enacting any behaviour, people move across an intention–behaviour gap (Sniehotta, Scholz & Schwarzer 2005). Being alert to expressed barriers, to expressions of self-talk from participants and to the phrases people use assists in identification of motivational level. The five stages of change proposed in the transtheoretical model of change (Prochaska & Velicer 1997) are used in some approaches as a tool for identifying motivational level. In the framework considered here (Figure 22), it is suggested that this be simplified to three levels: refusing to act, intending to act and deciding to act, with a temporal dimension indicated by the individual.

My research highlighted the different motivational sources people draw upon when undertaking exercise and the different levels of motivation. It pointed to the need to offer alternatives: to offer a programme with exercise as the only option, or to offer one without exercise is to deny choice and to deny a recognition that people are motivated by differing sources. As participants in my study noted, some people need the external sources of motivation and the group processes that the experience of supervised exercise brings. Others were able to adopt and follow an exercise regime independently, suggesting a stronger internal motivation. In acknowledging motivational levels and tailoring the interaction to that orientation, barriers to, and facilitators for, behaviour can be explored. Ultimately, behaviour management must come from within the individual and behaviour imposed externally is seldom successful (Rollnick & Miller 1995). The proposed model recognises and respects this.

Evaluating engagement

The Ambulatory Care Experiences Survey (Safran et al. 2006) has been used in general practice to measure the participants' experiences of eliciting preferences (Rodriguez et al. 2008). Alternatively, this element could be simply evaluated by asking participants and families if enquiry was made as to their preferences and if these were included in decision-making. Similarly, a simple question of participants and health professional would ascertain if enquiry as to what people are doing to manage has occurred.

E4.2.3 Negotiation

Collaborative definition of goals is referred to as ‘finding common ground’ (Brown, Weston & Stewart 1989) or as collaborative identification of ‘problems’ in the chronic disease management literature (Battersby et al. 2003; Von Korff et al. 1997). This also allows the health professional to marry the participant’s priorities with clinical priorities. It is also important to address ‘what is going well’, that is to ascertain what the person currently does to manage health and to affirm efforts and encourage maintenance of positive health behaviours as well as identifying areas of mutual concern. Once goals—for example, problems/issues/health behaviours to be maintained—are defined, the way is paved for negotiating actions to achieve the goals.

Negotiating a plan is referred to in the general medical practice literature as ‘informed shared decision-making’ (Coulter & Ellins 2007; Elwyn 2006; Elwyn & Charles 2001; Stewart 2001; Toop 1998; Towle & Godolphin 1999; Weston 2001), and as ‘collaborative management’ in the chronic disease management literature (Von Korff et al. 1997). Negotiation and active involvement in care will occur along a continuum, depending upon the acuity and severity of the condition, the participant preferences, their skills and the extent to which they wish to participate. Degree of involvement will also change with the changing contexts of people’s lives. A recent Swiss study (Langewitz, Nubling & Weber 2006) notes that while the majority of inpatients preferred physicians to make decisions, individual preferences should nevertheless be ascertained. Making informed shared decisions could be seen as a process outcome of participant-centred engagement in healthcare.

The provision of information is integral to making informed decisions. Information should be relevant to the participant’s needs, requests and health literacy. Provision of information may also be in the form of access to medical records, which has been shown in a review published in 2002 to enhance communication in the clinical encounter, with potential adverse effects such as increased participant concern or confusion found to be minimal (Ross & Lin 2003). Discussion of the pros and cons of the suggested course of action together with alternatives (Elwyn et al. 2004; Wagner, Austin & Von Korff 1996; Weston 2001) can be facilitated by patient decision aids that have been found to improve knowledge, understanding and congruence between what people value and what they choose (O’Connor et al. 2003). Finally, it should be ensured that the decision is accepted and understood by both parties (Weston 2001).

Training in specific skills should be available for both participant and healthcare provider. Such skills may include learning recognised self-management skills (Table 42) such as problem-solving skills (Figure 21) to aid the identification of areas of mutual concern, setting action plans to achieve goals (Table 44) and identifying barriers to achieving goals. Health professionals may need to refine specific interviewing skills and participants may need to learn communication skills which enable them to assert their preferences (Table 43). Additionally, participants may need to learn symptom management, including interpretation of self-monitoring that has been positively associated with improved physiological measures, such as blood glucose and blood pressure, and health status in

terms of general health, days lost from work, number of health problems and functional limitations (Kaplan, Greenfield & Ware 1989).

Evaluating negotiation

Evaluation of satisfaction with information is met in part by existing questionnaires. The CQI-2 (Mercer & Howie 2006) implies these needs have been met in that enablement measures an understanding of, and coping with, health concerns. However, it does not specifically ask this question. The General Practice Assessment Survey (GPAS) (Ramsay et al. 2000) addresses satisfaction with information but not skills training such as how to set an action plan. The Observing Patient Involvement Scale (OPTION) (Elwyn et al. 2003) has a number of observer-rated questions which could be adapted for participant or health professional self-report. Alternatively, satisfaction with the degree of information and skills training could be evaluated by asking these questions.

E4.2.4 Taking action to achieve goals

Setting an action plan provides the route to be followed to realise the agreed goals from the interaction (Tables 44 and 45). Action planning may be seen as both a strategy and a skill. Planning to achieve goals is a strategy involved in the self-regulation of behaviour (Bandura 1986), and people require the skill to set the plan in order to implement it. In my research, interviewed participants frequently attributed their adoption of exercise or increased activity levels to action planning. That is, movement across the intention–behaviour gap (Sniehotta, Scholz & Schwarzer 2005) was enhanced.

Evaluating taking action

Setting with action plans should be recorded in notes and a copy given to participants. Databases can be established to facilitate this. Electronic records enable quick retrieval and analysis of these plans for follow-up, quality improvement or research purposes. Participants and health professionals could be asked if discussion of goals and action plans occurred at interactions.

E4.2.5 Repeating back

Ensuring that both participant and health professional agree to and understand decisions is an important aspect of the partnership (Weston 2001) and may be achieved by repeating back (Figure 22). This communication skill, wherein a précis of the conversation is repeated back to the speaker, aids clarification of aspects of a discussion. Specific requests may be repeated back to ensure understanding.

Evaluating repeating back

Understanding has been captured by the enablement questions of the CQI-2 (Mercer & Howie 2006). Alternatively, direct questions relating to this could be asked.

E4.2.6 Establishing collaboratively planned follow-up

Finally, a participant-centred framework should include sustained, proactive and planned follow-up arrangements (Von Korff et al. 1997) so that monitoring of the condition and reinforcement of

participants' progress may occur (Bauman 2003). The nature of follow-up (telephone, email, letter, appointment) should be decided in concert with the participant and the plan recorded in the notes.

Evaluating establishment of planned follow-up

Participants could be asked if follow-up was arranged and if it occurred as planned.

E5 Conclusion

The following Table 47 details an example of application of the CENTREd Framework, with suggestions of how the skills and tools might be woven into the interaction. Exercise is used as an example of a health behaviour from the SNAPPS 'menu' of health behaviours. It is recognised that the framework would now need to be evaluated by quantitative and qualitative means, from participant and healthcare provider perspectives. Two questionnaires which measure the elements of the PCEH described above follow Table 47.

In conclusion, the CENTREd Framework may be brought to any healthcare interaction, and its strategies applied according to the enablers and barriers relating to personal skills, to the facility and to the system within which that facility is embedded.

Table 47: Applying the 'CENTRED' Framework

'CENTRED'	Strategies	Examples of Questions
Commit and 'Connect'	<p>Open-ended questions: <u>Establish rapport:</u> following introductions, invite description of what is happening in the person's life. <u>Try to 'connect' on a personal level:</u> consider psychosocial, cultural and educational background. Include family / carer.</p>	<p>'Tell me what has been happening with you.' Or, 'Tell me what matters for you at the moment.' 'Tell me what interests/hobbies/work you have.' 'Tell me who is at home..... Oh, you have [four sons?]...... I have [four daughters].' 'Tell me what interests / hobbies / work you have.' 'How would you like your family involved?'</p>
Engage	<p>Open-ended questions: <u>Invite description of preferences, ideas, feelings and expectations.</u> Be alert to phrases suggesting motivational orientation. Be alert to negative self-talk.</p> <p>At all stages ensure mutual understanding.</p>	<p>'If you had a crystal ball/magic wand and could see your life differently, how would you see it? What, if anything, would you change?' 'Tell me what condition you have'. The person may name the condition with the greatest impact. 'What effect has this had on how you live your life? on how you feel?.....on how you see yourself?' 'What do you think is causing your [increased breathlessness]? Tell me how this affects you?' ' Tell me what you would like to do.' 'What are you hoping I might help you with?'</p>
Negotiate	<p>Affirm, Define, Address, Decide: <u>Identify and acknowledge / praise</u> what the person is currently doing to manage their health. Enquire about specific health behaviours (SNAPPS framework). Build upon this. Acknowledge any difficulties / resistance.</p> <p><u>Define areas of mutual concern.</u> Use open-ended questions and / or tools such as the Partners in Health Questionnaire to identify areas of health requiring attention. Identify importance. The 'behavioural ruler' is a useful tool if people are erecting barriers to change. Use problem solving to identify solutions. Consider possible futures.</p> <p><u>Address condition-specific and general health behaviours</u>, if not previously identified. Offer a 'menu' of choices, e.g., SNAPPS.</p> <p><u>Provide information / teach skills</u> and discuss benefits / risks, invite preferences. <u>Mutually decide and prioritise goals</u> to be addressed.</p> <p>Reflective listening and Summarise: Enables clarification, displays empathy and acknowledgement. This skill is used throughout the interaction.</p>	<p>'I see you are gaining some weight. Well done!!! I guess eating must be difficult when you are really breathless. How are you going with the [nutritional] supplements?' 'Tell me what you are doing now for [exercise]... You have done so well walking to the corner shop four days this week. Well done!!!! Tell me what you plan to do next....It must be difficult when [you are tired].' 'I understand you want to [get fit]. That is great. Getting fit is important for your health.' 'I see from this questionnaire that you are having some trouble with [physical activity].' 'Tell me on a scale of zero to 10 how important [exercise] is for you.'</p> <p>'If zero is doing no [exercise], and 10 is [exercising each day], where are you on this scale? Why a [three] and not a [one]? What would get you to a [six]?..... Let's look at ideas to get to a [six].' 'How do you think you will feel if you do not [exercise] / do some [exercise] each day?'</p> <p>'We know there are some things you can do to help you have more control over your [COPD] and health. Let's look at those. What one or two would you like to start with?'</p> <p>'I have some tips here on [starting exercise]. The good news about exercising is..... the not so good news is... What would you like to do about that?' 'You said you are feeling really down. It's a good idea to look at [your mood concerns] first. What if next time we look at [exercise and weight management] if we do not have time today?'</p> <p>'I see... [your breathlessness varies during the day so coming to the gym at a set time when you might be very breathless would not be useful]. That must be difficult. Let's look at what you might like to do.'</p>

Table 47 continued

'CENTRED'	Strategies	Examples of Questions
<p>Taking Action</p> <p><u>Re-visit</u> what it is the person would like to do (in their words).</p> <p><u>Explain the notion of goals and action plans.</u> The GOAL is the destination; the ACTION PLAN is the map.</p> <p><u>Invite the participant to complete a written 'SMART' action plan</u> if their conversation indicates they are deciding to act.</p> <p><u>Facilitate setting an action plan.</u> if the conversation has indicated the person is resistant to formal plans and routines.</p> <p>Example Goal SMART Action Plan Specific: a specific goal-related behaviour. Measurable: How much: duration, cost, size, amount? When: for example, time of day? How often: frequency per day / week? Attainable: challenging and realistically achievable / confident Relevant: something the person wants to do / important to them Time-specific: a defined time by which it is to be achieved.</p>		<p>'You have told me you would like to [get as fit as a trooper].'</p> <p>'Getting [fitter] is a goal. It does not tell us exactly what you would do to [get fitter]. Tell me what activity you would like to do to [get fitter...walk the dog in the afternoon....great idea!]</p> <p>'Let's look at this further. You might like to write down what you want to do.'</p> <p>Example form practice: 'You noticed climbing stairs is a problem. Let's look at what is getting in the way..... you say your legs feel like jelly? There are some exercises which can help, and I see you do not like regimented exercise. Let's look first at how you fill your day....Sitting at the computer a lot.... You get up from the desk at least ten times a day....would there be anything stopping you from sitting down and standing up again when you have finished your work / before you go to have lunch / watch the television? Great! You think you could do this. How many repetitions of sitting to standing could you do? Good! How many times a day could you do those repetitions? Do you mind if I write this down so I don't forget?'</p> <p>Example of recording the above conversation with the participant, 'repeating back' each step to clarify. Goal: 'You want to have stronger legs so climbing stairs is easier.' Fitting the SMART Action Plan Specific: You are going to do sitting to standing Measurable: You will do six repetitions, after finishing on the computer, before lunch, before the afternoon movie and before dinner. on Monday, Wednesday, Thursday. Attainable: You are eight out of ten confident you can do this. Relevant: It is seven out of ten important to you. Time-specific: You will have achieved six repetitions three times a day by the end of the week. You are aiming to climb the stairs without stopping by the end of three months. Fantastic! There is a plan we can use to keep track of how well you are doing.'</p>
<p>Repeating back</p>	<p>Ensure needs and preferences were met. Ensure understanding. Repeat back decisions and actions.</p>	<p>'Tell me what else we need to cover....Is there anything I need to go over again?'</p> <p>'We have decided to work on [exercise]. Your plan is..... I look forward to seeing how well you managed.'</p>
<p>Establish follow-up</p>	<p>Decide when and how follow-up will occur: appointment/ telephone / letter / home visit / email. Respect for participant preferences is central to 'CENTRE'</p>	<p>'Let's look at when we can meet / talk again.' 'How would you like us to meet up again?'</p> <p>Ultimately it is the participant's CHOICE.</p>

Date

PARTICIPANT'S VIEW OF PARTNERSHIP

We are interested in learning how you perceive your experiences with your health professionals. This will help us to improve our practice in the future. Please CIRCLE the appropriate NUMBER.

1. Working in partnership with my health professional is important to me.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

For the following questions, over the LAST FOUR VISITS, have you experienced the following as part of your visit with your healthcare professional:

2. The health professional and I work together to look after my health.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

3. My family or carers were invited to be part of the discussion about my health.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

4. I was asked by my health professional what was important to me.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

5. The health professional understands how the condition affects my life.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

6. I felt that I was listened to during the visit with the health professional.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

7. I trust the health professional to treat me in a courteous, sympathetic, respectful way.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

8. I trust the health professional to maintain confidentiality.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

9. I was asked what I am currently doing to look after my health.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

10. I was asked about my preferences for healthcare.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

11. My preferences for healthcare were respected.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

12. I was offered choices about my health care.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

13. I was not 'pushed' to do something I do not want to do.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

14. I was provided with sufficient information I could understand.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

15. I was given the opportunity to practice new skills (such as using puffers, how to record my blood sugar, steps for solving problems.)

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

16. Problems or concerns were decided together.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

17. My goals for my health were discussed together.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

18. I made or discussed an action plan to achieve my goal(s).

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

19. The health professional asked me to repeat back my understanding of the decisions / discussion.

0	1	2	3	4	5	6	7	8	9	10
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Zero = Not at all

Some of the time

10 = All of the time

20. Plans for follow-up were agreed upon.

0	1	2	3	4	5	6	7	8	9	10
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Zero = Not at all

Some of the time

10 = All of the time

Date

HEALTH PROFESSIONAL'S PERSPECTIVE ON PARTNERSHIP

We are interested in learning how you perceive your current practice. This will help us to target our training in the future. Please CIRCLE the appropriate NUMBER.

1. Working in partnership with my clients is important to me.

0	1	2	3	4	5	6	7	8	9	10
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Zero = Not at all

Some of the time

10 = All of the time

For the following questions, in the LAST FOUR WEEKS, have you done the following as part of your clinical practice:

2. I worked in partnership with my client to look after their health.

0	1	2	3	4	5	6	7	8	9	10
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Zero = Not at all

Some of the time

10 = All of the time

3. I invited family or carers to be part of the discussion about the client's health, with their permission.

0	1	2	3	4	5	6	7	8	9	10
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Zero = Not at all

Some of the time

10 = All of the time

4. I asked my client what was important to them.

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Zero = Not at all

Some of the time

10 = All of the time

5. I asked my client about their understanding of their condition.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

6. I asked my client what they currently do to look after their health.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

7. I enquired about my client's preferences for healthcare.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

8. I respected my client's preferences for healthcare.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

9. I offered my clients choices about their healthcare.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

10. I told my clients what to do.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

11. I provided my clients with sufficient information they could understand.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

12. I gave my clients the opportunity to practice new skills (such as using puffers, how to record their blood sugar, steps for solving problems.)

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

13. Problems or concerns were decided together.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

14. I discussed with my client goals for their healthcare.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

15. I discussed or facilitated making an action plan with my clients to achieve their goal(s).

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

16. I asked my clients to repeat back their understanding of the decisions/discussion.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time

17. I negotiated follow-up with my client.

0 1 2 3 4 5 6 7 8 9 10

Zero = Not at all Some of the time 10 = All of the time