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EXERCISE PARTICIPATION IN  
PARKINSON'S DISEASE:  
A QUALITATIVE STUDY

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BAppSc (Phty), Dip Ed

**A THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS**

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## CANDIDATE'S STATEMENT

I, CHRISTINE JANE O'BRIEN, hereby declare that the work contained within this thesis is my own and therefore, to the best of my knowledge and belief, original except as acknowledged within the text. I declare that the material contained within this thesis has not been submitted to any other university or institution as a part or a whole requirement for any higher degree.

I, CHRISTINE JANE O'BRIEN, declare that I was the principal researcher of all work included in this thesis, including work published with multiple authors. In addition, ethical approval from The University of Sydney Human Research Ethics Committee was granted for the study presented in this thesis. Participants were required to read a participant information document and written informed consent was gained prior to data collection.

Name: Christine O'Brien

Signed:

A handwritten signature in black ink, appearing to read "Christine O'Brien". The signature is written in a cursive style with a large initial 'C' and 'O'.

Date: 10<sup>th</sup> August 2014

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## **PUBLICATIONS AND PRESENTATIONS**

Parts of the work presented in this thesis have been published and/or presented in the following forums.

### **PUBLISHED ABSTRACTS**

- O'Brien CJ, Canning CG, Clemson L. The experience of exercise in Parkinson's disease. Proceedings of the Australian Capital Territory Australian Physiotherapy Association Research Symposium 2011; p15.  
*Platform presentation at the Australian Capital Territory Australian Physiotherapy Association Research Symposium, 17<sup>th</sup> September 2011, Canberra, Australia.*  
*This presentation won "Best student paper".*
- O'Brien CJ, Canning CG, Clemson L. The experience of exercise in Parkinson's disease: preliminary results. Proceedings of Parkinson's Australia National Conference, 2012; p28.  
*Platform presentation at the Parkinson's Australia National Conference, 13<sup>th</sup> & 14<sup>th</sup> July 2012, Brisbane, Australia.*  
*This presentation won a "Rising Star" award from Parkinson's Australia.*
- O'Brien CJ, Canning CG, Clemson L. Parkinson's disease: the experience of exercise. Proceedings of the 17<sup>th</sup> International congress of Parkinson's disease and Movement Disorders, 2013; p72.  
*Poster presentation at the 17<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders, 16-20<sup>th</sup> June 2013, Sydney, Australia.*
- O'Brien CJ, Canning CG, Clemson L. A Parkinson's disease-specific physiotherapy exercise program from the participant's perspective. Proceedings of the Australian Capital Territory Australian Physiotherapy Association Research Symposium, 2013; p19.

*Platform presentation at the Australian Capital Territory Australian Physiotherapy Association Research Symposium, 7<sup>th</sup> September 2013, Canberra, Australia.*

- O'Brien CJ, Canning CG, Clemson L. A 6-month exercise program for people with Parkinson's disease: the participants' perspective. Proceedings of the Australian Physiotherapy Association Biennial Conference 2013; p124

*Platform presentation at the Physiotherapy Conference 2013 (National Neurology Group), 17-20<sup>th</sup> October 2013, Melbourne, Australia.*

### **MANUSCRIPT PREPARED FOR SUBMISSION**

O'Brien CJ, Canning CG, Clemson L. Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson's disease: a qualitative enquiry. Prepared for submission to *Disability and Rehabilitation*.

### **ORAL PRESENTATIONS**

O'Brien CJ, Canning CG, Clemson L. Barriers and facilitators to exercise participation in Parkinson's disease.

Platform presentation to Goulburn branch of Parkinson's Australia support group, 11<sup>th</sup> October, 2012, Goulburn, Australia.



## **ABSTRACT**

Exercise and physiotherapy have been found to improve mobility and health related quality of life in people with Parkinson's disease and exercise is now recommended as an important component of the management of the disease. People may live with Parkinson's disease for many years and it would appear that to maximise the benefits of exercise, individuals would need to participate in exercise regularly over the course of the disease. People with Parkinson's disease have a range of motor and non-motor impairments that could potentially impact on exercise participation but there is limited evidence about the factors that influence exercise participation in this population. It would seem important for physiotherapists to understand factors that impact on exercise participation so that exercise programs can be developed for people with Parkinson's disease that encourage uptake and sustained participation.

A qualitative enquiry was conducted to explore the experience of eight participants who had recently completed a semi-supervised, 6-month falls prevention exercise program. The aim was to understand the participants' meaning of exercise and to better understand how factors influencing exercise participation interact and impact on decisions made about whether to exercise or not. In-depth semi-structured interviews were conducted and analyzed using grounded theory methodology.

It was found that exercise participation can assist in reframing identity as individuals are faced with losses associated with ageing and Parkinson's disease. Three new influences on exercise participation were identified, namely the non-motor impairments of apathy and fatigue, a belief in a finite energy quota, and the importance of feedback. It was found that

decisions about whether to exercise were the result of a complex and dynamic process of evaluation by the participants in which goals were crucial. A model was developed to explain the interaction of the factors involved in making decisions regarding exercise participation.

This thesis contains information on how individual factors interact and influence exercise participation in individuals with Parkinson's disease as well as suggestions on how to address these in the clinical setting. The model of interacting factors influencing exercise participation developed in this study needs to be tested more broadly to determine whether it explains exercise participation of people with Parkinson's disease in those individuals with more mild and more severe disease, as well as those who are sedentary. In addition, it is important to determine whether yet unidentified factors influence the exercise experience of these individuals.

# **CHAPTER 1: INTRODUCTION**

## **INTRODUCTION**

### **PARKINSON'S DISEASE: PREVALENCE AND HEALTH COSTS**

### **EXERCISE IN THE MANAGEMENT OF PARKINSON'S DISEASE**

### **MODELS FOR PHYSICAL ACTIVITY AND BEHAVIOUR CHANGE**

**International classification of function and disease**

**Physical activity for people with a disability model**

**Bandura's psychosocial model of health behaviour**

### **FACTORS INFLUENCING PHYSICAL ACTIVITY AND EXERCISE**

**Older people**

**People with chronic disease and disability**

**People with Parkinson's disease**

*Self-efficacy*

*Belief in the benefits of exercise for Parkinson's disease*

*Outcome expectations and realisations*

*Social support*

*Health professional advice*

*Type of exercise program*

*Health conditions other than Parkinson's disease*

*Transport*

*Time*

*Environment*

*Motor impairments*

*Non-motor impairments*

### **RESEARCH QUESTIONS**

### **REFERENCES**

## **Exercise**

*Activity requiring physical effort, carried out to sustain or improve health and fitness*

*“Well, you look at small children rolling along the grass and doing roly-polys or hands-over catherine-wheel type things and they are laughing and giggling and challenging one another. That’s what exercise is all about.”*

### **INTRODUCTION**

Parkinson’s disease is a chronic degenerative neurological disease affecting mainly people over the age of 65 years. There is evidence to support the use of exercise in the management of the disease, however, less is known about what exercise means to people with Parkinson’s disease and how factors influence their participation in exercise. This thesis reports a qualitative study designed to explore the meaning of exercise and how factors interact and influence decisions regarding exercise participation in people with Parkinson’s disease. This chapter will provide background regarding prevalence and costs associated with Parkinson’s disease as well as evidence of the efficacy of exercise in this population. Certain conditions are required to initiate and sustain healthy behaviours such as exercise participation and models have been developed to define these conditions and illustrate their interactions. Some of these models will be presented, including those specifically addressing physical activity in people with disabilities. Some evidence exists regarding motivational factors and barriers to physical activity and exercise in healthy older people and people with chronic disease and disability. This evidence will be considered, as it is likely to be applicable to people with Parkinson’s disease. Finally, the particular motor and non-motor impairments experienced by people with Parkinson’s disease and what is currently known about factors that influence exercise participation in this population will be presented as background to the specific research questions addressed in this thesis.

## **PARKINSON'S DISEASE: PREVALENCE AND HEALTH COSTS**

Parkinson's disease is the second most common degenerative neurological disease after Alzheimer's disease (Mellick, 2013). It is difficult to get worldwide figures, however, a study investigating the prevalence of Parkinson's disease in western Europe's five, and the world's ten, most populous nations found there were an estimated 4.1-4.6 million people over 50 living with the disease and this was predicted to increase to 9 million in 2030 (Dorsey et al., 2007). These figures are reflected in Australia with an estimated 54,700 people living with the disease in 2005 at an estimated prevalence in the total Australian population of 283 per 100,000 (Access Economics, 2011; Mellick, 2013). Parkinson's disease is a multisystem neurodegenerative disorder associated with both motor (tremor, rigidity, bradykinesia, akinesia and balance impairment) as well as non-motor impairments such as depression, sleep disturbances and pain (National Institute of Neurological Disorders and Stroke, 2013). These impairments are associated with a gradual deterioration in mobility and independence, often leading to periods of hospitalisation and the need for community and residential care (Porter et al., 2010). Due to these factors the health cost of Parkinson's disease is high and was \$478.5 million in Australia in 2011 (Access Economics, 2011) and \$US14 billion in the United States in 2010 (Kowal et al., 2013). As well, there are other significant costs associated with reduced productivity of people with Parkinson's disease and their carers (Access Economics, 2011; Kowal et al., 2013).

## **EXERCISE IN THE MANAGEMENT OF PARKINSON'S DISEASE**

Although the mainstay of treatment is pharmacological, there is a growing body of evidence, including several systematic reviews with meta-analyses, demonstrating the additional benefit of exercise for people with Parkinson's disease. Exercise and physiotherapy have been shown to be effective in improving mobility and health-related quality of life (Goodwin et al., 2008). Improved mobility includes increases in walking speed and endurance (Goodwin et al., 2008; Tomlinson et al., 2012) as well as improvement in balance (Allen et al., 2011). Exercise can also increase muscle strength (Lima et al., 2013) and emerging evidence suggests that balance-demanding exercise in the form of Tai Chi can reduce falls which are a common problem in this population (Li et al., 2012). These benefits have been shown to occur in the mild to moderately severe stages of the disease (Goodwin et al., 2008; Tomlinson et al., 2012). It is possible that exercise could also have a neuroprotective effect by promoting reversal in dopaminergic neuron loss leading to a slowing of disease progression. This has been demonstrated in animal models (Choe et al., 2012; Grazina & Massano, 2013) and there is emerging evidence in humans (Fisher et al., 2013).

Due to these factors, exercise is now recommended as an important component of the management of Parkinson's disease in the mild to moderately severe stages (Earhart & Falvo, 2013; Kaplan & Tarsy, 2013). People may live with Parkinson's disease for many years and it would appear that to maximise the benefits of exercise, individuals would need to participate in exercise regularly over the course of the disease.

## **MODELS FOR PHYSICAL ACTIVITY AND BEHAVIOUR CHANGE**

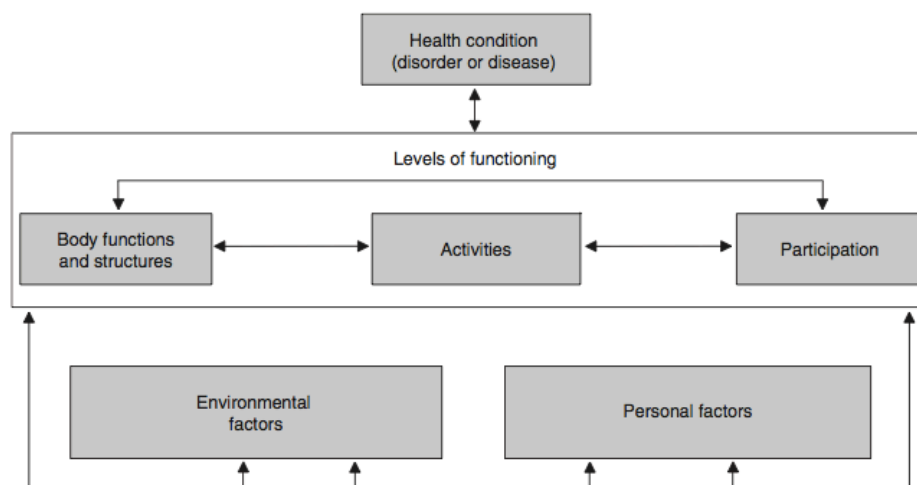
Physical activity and exercise are two commonly used terms and it is helpful to be aware of the distinction between the two. Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure (Schutzer & Graves, 2004). Physical activity for adults includes recreational physical activity, walking, cycling, occupational activities, household chores, games, sports or planned exercise (World Health Organisation, 2010a). Exercise is a structured component of physical activity which aims to improve one or more aspects of physical fitness (Schutzer & Graves, 2004). The current study focuses particularly on exercise participation, however, as exercise is a subset of physical activity, the literature on both exercise and physical activity will be drawn upon. Participation in regular physical activity is recognised as an important factor in preventing chronic disease and the promotion of health and well-being (World Health Organisation, 2010a). Researchers have recognised the need to develop frameworks to examine the complex and interacting factors that influence exercise participation and three relevant models will be presented in the next section.

### **International classification of function and disease**

The most commonly used framework to model the relationships between functioning, disability, the health conditions of the person and their environment is the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2010b). This model classifies factors that impact on an individual's participation in their life situation, which includes physical activity and exercise participation. It identifies three domains of function and factors that impact on these in a complex and dynamic way (See Figure 1.1). The three domains of function are body functions and structures, activities and participation (World Health Organisation, 2010b). The three factors impacting on these

areas of function are health condition, personal factors and environmental factors. Health condition is self-explanatory and personal factors include characteristics such as age, race, lifestyle, education, employment, coping styles and past and current experience. Environmental factors include the person's macro-environment such as infrastructure, laws and regulations and their micro-environment such as their physical and social environment in the home and for work and leisure (World Health Organisation, 2010b). Some factors in each of these categories are modifiable while some such as age and sex cannot be modified. The ICF is the first world standard providing a broad conceptualisation of functioning and disability (World Health Organisation, 2010b).

**Figure 1.1.** Model of functioning and disability from the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2010b).



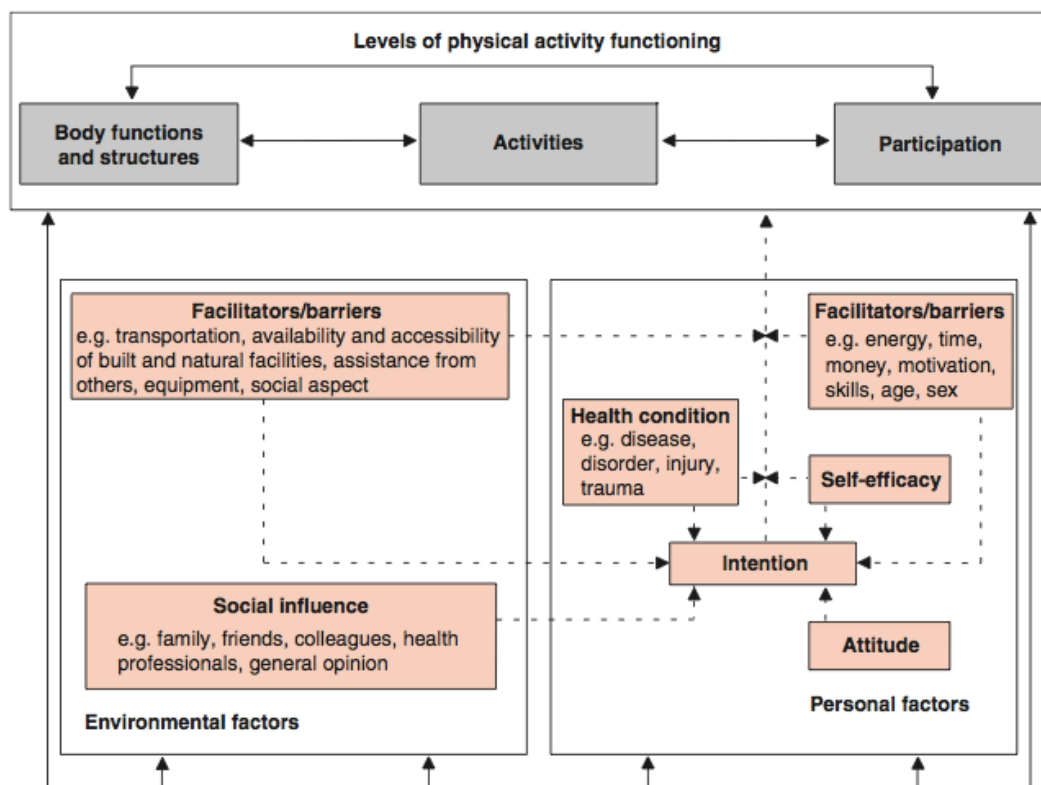
### **Physical activity for people with a disability model**

A physical activity model has been developed specifically for people with a disability (PAD) incorporating both the ICF model and the Attitude, Social Influence and self-Efficacy (ASE) model of physical activity behaviour (van der Ploeg et al., 2004). This



model extends the ICF model and applies it specifically to factors influencing physical activity (Figure 1.2). It explicitly identifies factors such as self-efficacy and social influence that are implicit in the ICF model. This is useful as a starting point in understanding potential factors influencing physical activity in people with Parkinson's disease. However, the factors identified should not be considered to be exhaustive, as important disease-specific factors may be missed.

**Figure 1.2.** The Physical activity model for people with a disability (PAD) (van der Ploeg et al., 2004)

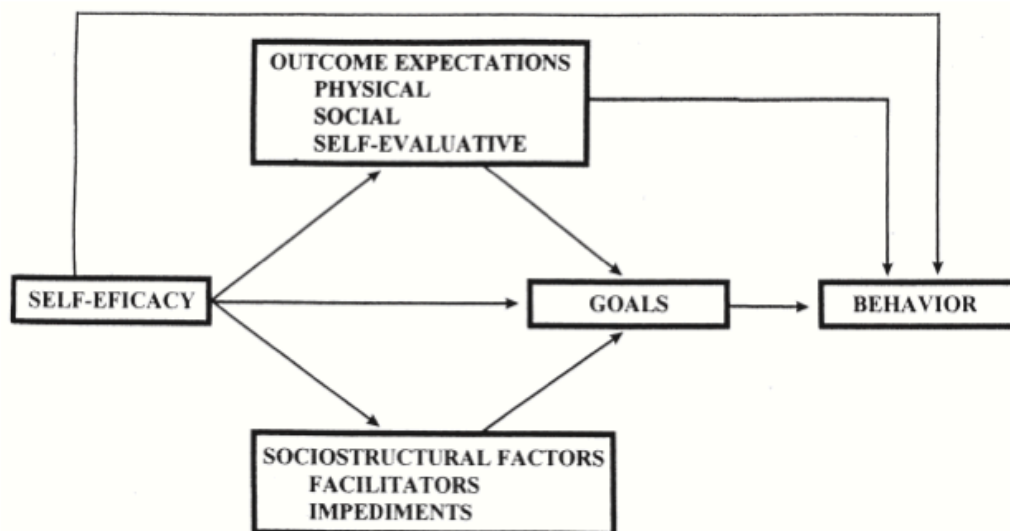


### **Bandura's psychosocial model of health behaviour**

The psychosocial model of health behaviour looks more broadly than the outcome of functioning and physical activity participation addressed in the ICF and PAD models and provides a theory for understanding how individuals can exert control over their health

behaviour to achieve a sense of well-being (Bandura, 2004). This model of health behaviour is based on social cognitive theory and explains the regulation of behaviour and motivation through the interaction of five psychosocial factors (Figure 1.3). Self-efficacy, which is the belief one can successfully carry out actions to achieve a goal (Bandura, 1998), is the most crucial factor in this model. It acts both directly on health behaviour and indirectly through its influence on the other factors: outcome expectations, goals and sociostructural facilitators and impediments. The relationships between these determinants are shown in Figure 1.3

**Figure 1.3.** Psychosocial model of health behaviour (Bandura, 2004)



All three models outlined above place emphasis on the potential complex interactions between factors influencing physical activity or more broadly health behaviours. Nevertheless, much of the research investigating factors influencing physical activity and exercise participation to date, focuses primarily on identifying facilitators and barriers to exercise participation. Only a small number of studies aim to explain physical activity and

exercise behaviour by exploring interactions between factors and concepts identified in these models. This research, as it pertains to older people, to people with chronic disease and disability and to people with Parkinson's disease will be presented in the following section of this chapter.

## **FACTORS INFLUENCING PHYSICAL ACTIVITY AND EXERCISE**

### **Older people**

It has been recognised that implementing physical activity and exercise programs for older adults requires consideration of issues that may be specific to this population and as people with Parkinson's disease tend to be older, these considerations may be relevant for them.

Self-efficacy has been consistently associated with exercise participation and physical activity in older people (Chase, 2013; McAuley et al., 2003; Resnick & D'Adamo, 2011; Schutzer & Graves, 2004; Sniehotta et al., 2013). Other factors have been found to indirectly influence physical activity through their effect on self-efficacy. These factors include social support (McAuley et al., 2003; Resnick et al., 2002; Sniehotta et al., 2013) as well as mental health, environmental and weather variables (Sniehotta et al., 2013).

Outcome realisations, or the perceived benefits of the exercise experience, have also been directly linked to sustained participation in physical activity in older people and are thought to directly affect self-efficacy (Brassington et al., 2002; Resnick & D'Adamo, 2011). Other factors positively correlated with physical activity participation in this population include advice from a trusted health professional (Biedenweg et al., 2013; Schutzer & Graves, 2004), deteriorating health, having more time (Schutzer & Graves, 2004) and enjoying being with others (Biedenweg et al., 2013; Schutzer & Graves, 2004). Barriers to physical activity include lack of motivation (Biedenweg et al., 2013; Justine et al., 2013), lack of knowledge of the benefits of exercise (Schutzer & Graves, 2004) and

poor health (Schutzer & Graves, 2004; Sniehotta et al., 2013). It is notable that deteriorating health has been identified as both a motivator and a barrier to physical activity in older people suggesting that the context of factors is important. Interestingly some of the barriers to participating in organised exercise programs are different from those for physical activity participation in general, possibly reflecting the structured time commitment perceived to be involved in scheduled exercise programs. Barriers identified specific to scheduled exercise programs are that people felt they were already getting enough exercise from everyday activities (Biedenweg et al., 2013; Justine et al., 2013) or that they didn't have enough time (Justine et al., 2013).

### **People with chronic disease and disability**

As well as providing benefits to the general population, regular participation in physical activity has been shown to be effective in maintaining health, reducing the risk of secondary health problems and improving or maintaining function in people with chronic disease and disability (Rimmer, 2006; van der Ploeg et al., 2004). It is recognised that encouraging people with chronic disease and disability to participate in regular physical activity requires consideration of both similar and different issues to those in the older population. Factors influencing physical activity common to both older people and those with chronic disease and disability are social support, the enjoyment and social interaction gained from exercising with others (Allen et al., 2004; Dodd et al., 2006; Hendry et al., 2006; Mudge et al., 2013), self-efficacy (Kasser, 2009; Morris et al., 2012), outcome realisations (Allen et al., 2004; Dodd et al., 2006; Hendry et al., 2006; Kasser, 2009), knowledge about exercise (Hendry et al., 2006; Kasser, 2009; Mudge et al., 2013), advice from a trusted health professional (Hendry et al., 2006; Mudge et al., 2013) and health condition (Hendry et al., 2006; Kayes et al., 2011; Morris et al., 2012; Mudge et al., 2013;

Rimmer et al., 2008). Factors specific to people with chronic disease and disability are individualised instruction, belief in exercise as a means of exerting control over the disease or disability, the reliance on others, cost and transport (Kasser, 2009; Mudge et al., 2013; Rimmer et al., 2008). Like those factors identified in influencing physical activity in older people, factors may be motivating influences in some circumstances and barriers in others.

Social support is an influence on physical activity in older people but reliance on others for support in engaging in physical activity is an even stronger theme in the literature on people with chronic disease and disability, possibly reflecting their increased dependence on others due to motor and non-motor impairments. This support includes emotional support provided by others with similar problems in the exercise group, assistance with transport and encouragement from family, carers and physiotherapists (Kasser, 2009; Morris et al., 2012; Mudge et al., 2013; Taylor et al., 2004). The enjoyment and sense of well-being gained from exercising with others with similar disabilities is also a common theme in this population with this being valued more highly than improvement in physical ability in several studies (Allen et al., 2004; Mudge et al., 2013; Pentecost & Taket, 2011; Stretton et al., 2013). Self-efficacy for exercise has not been extensively investigated in people with chronic disease and disability but has been found to assist in maintenance of physical activity in people with multiple sclerosis (Kasser, 2009) and stroke (Morris et al., 2012). Participants with multiple sclerosis reported that self-efficacy for exercise was enhanced by learning from exercising with others with similar disability and also from goal attainment (Kasser, 2009).

Another motivating influence for exercise participation in people with disabilities is belief in the benefits of exercise, particularly as a means of exerting control over the disease or disability, in order to maximise their participation in everyday activities (Hendry et al., 2006; Kasser, 2009; Mudge et al., 2013). Positive physical activity beliefs have been found to be associated with physical activity participation in people with stroke (Morris et al., 2012), multiple sclerosis (Kayes et al., 2011) and knee osteoarthritis (Hendry et al., 2006). Past positive experience of exercise before the disability is generally considered to be motivating (Dodd et al., 2006; Hendry et al., 2006), but belief in the benefit of exercise for their particular condition appears to provide even more motivation. In fact, for some people, this belief was so strong that they felt they had no choice but to exercise whereas they had considered exercise to be optional before the onset of the disease or disability (Kasser, 2009; Stretton et al., 2013). Participants with multiple sclerosis stated that their goals of exercise participation had changed from general fitness and recreation prior to the onset of the disease to maintaining function after the disease onset (Kasser, 2009). Conversely, negative beliefs about exercise, such as individuals believing that exercise won't help their condition or that they already do enough exercise in their everyday activities, have also been identified in people with stroke, multiple sclerosis and knee osteoarthritis (Hendry et al., 2006; Kasser, 2009; Kayes et al., 2011; Rimmer et al., 2008) and these beliefs can lead to reduced motivation for physical activity. Fear of falling or injury was also reported to be associated with reduced physical activity in people with multiple sclerosis (Kayes et al., 2011). Furthermore, people with chronic disease have been reported to hold conflicting beliefs about physical activity and exercise that create tension when making decisions about physical activity and exercise (Kayes et al., 2011).

Outcome realisations, which is the perceived effect of the behaviour, also influences motivation for physical activity and exercise participation in people with chronic disease and disability. A reduction in knee pain (Hendry et al., 2006) and fatigue (Dodd et al., 2006), improved ability to participate in other activities (Allen et al., 2004), enjoyment (Allen et al., 2004; Dodd et al., 2006; Hendry et al., 2006), seeing the signs of progress (Dodd et al., 2006), and a sense of hope and optimism (Kasser, 2009) have been identified as positive outcome realisations of exercise programs for people with a disability.

Negative exercise outcome realisations such as an increase in pain, muscle soreness, fatigue and not improving as much as expected have also been reported in exercise programs for this population (Allen et al., 2004; Hendry et al., 2006). The influence of outcome expectations on physical activity and exercise participation is complex because participants might be aware of both positive and negative outcomes and they may value some outcomes more highly than others.

Knowledge about exercise is another identified influence on exercise participation in people with chronic disease and disability and this impacts on and helps to form beliefs about exercise. Knowledge about the benefits of exercise has been found to be a motivating influence on exercise participation in people with multiple sclerosis (Kasser, 2009) and patients in neurological rehabilitation setting (Stretton et al., 2013) by facilitating positive beliefs about exercise for their particular condition. Advice to participate in exercise from a health professional has been identified as a motivating factor in people with disability (Hendry et al., 2006; Mudge et al., 2013) and lack of knowledge of where and how to exercise has been identified as a barrier to exercise participation after stroke (Rimmer et al., 2008).

As in older people, state of health may be perceived as either a barrier or a motivating influence in people with chronic disease and disability. As mentioned previously, a belief that exercise can be beneficial and exert some control over disability can be a strong motivating influence, however, a health condition can also prevent people with a disability from exercising even in the presence of these beliefs. Lack of physical capability has been identified as a barrier to exercise participation in people with stroke (Rimmer et al., 2008) and knee osteoarthritis (Hendry et al., 2006) in the presence of a belief in the benefits of exercise for their condition. Fluctuating health status was also identified as altering the priority given to exercise in people with a physical, sensory or intellectual disability (Mudge et al., 2013) and multiple sclerosis (Kayes et al., 2011).

People with chronic disease and disability often have a unique combination of abilities and needs so it is unsurprising that individualised instruction is a commonly identified positive influence on exercise participation for this population (Dodd et al., 2006; Mudge et al., 2013). Participants reported that a “one size fits all” approach does not take into account their individual needs and is a barrier to physical activity participation. In contrast, a model where there is two-way communication between the individual and the exercise professional that results in an individualised program, even in a group situation, appears to enhance motivation (Mudge et al., 2013; Stretton et al., 2013). Linked with this is the positive impact of the exercise leader’s knowledge, expert advice and supervision on exercise participation (Hendry et al., 2006; Kasser, 2009).



Supervision has been identified as an important factor in encouraging participation in exercise programs in young people with cerebral palsy, adults with knee osteoarthritis and adults with chronic medical conditions (Hendry et al., 2006; Pentecost & Taket, 2011; Taylor et al., 2004). Despite acknowledging the importance of supervision, few studies have investigated it in more depth. Thus our understanding of what supervision means, what its important components are and how they impact on exercise participation is limited. The experience of supervision from the participant's perspective would appear to be the most useful way of investigating these concepts and some qualitative studies investigating semi-supervised home exercise programs for young people with cerebral palsy (Taylor et al., 2004) and group exercise programs for older adults with chronic medical conditions (Pentecost & Taket, 2011) have provided lists of meaningful aspects of supervision identified by the participants. Expertise, engagement in problem solving, providing feedback, progressing exercises, monitoring for safety, observing and offering emotional support have all been identified as important components of supervision by people with chronic disease and disability (Pentecost & Taket, 2011; Taylor et al., 2004).

The cost of programs and lack of transport have also been identified distinctly as barriers to physical activity and exercise participation in people with chronic disease and disability (Mudge et al., 2013; Nicholson et al., 2013; Rimmer et al., 2008). This most likely reflects the large percentage of these people who have limited financial resources and may not be able to drive or use public transport. Other barriers to exercise participation identified in a smaller number of studies are mental fatigue in people with multiple sclerosis (Kayes et al., 2011), lack of motivation in people with stroke (Nicholson et al., 2013; Rimmer et al., 2008), lack of energy due to the increased energy required to carry out everyday activities

in people with physical, sensory or intellectual disability (Mudge et al., 2013) and inability to physically access programs in the local community (Mudge et al., 2013).

In summary, many of the factors that influence physical activity and exercise participation in people with chronic disease and disability are similar to those identified for older people, however, there are important differences. The emphasis placed on enjoyment from exercising with others with similar disability, belief in the benefits of exercise to exert control over the condition, valuing individualised instruction, the impact of co-existing health conditions, cost, transport and the reliance on others for physical activity participation are factors reflecting the more complex range of abilities and needs of those with chronic disease and disability.

### **People with Parkinson's disease**

As people with Parkinson's disease have a chronic disease and disability and tend to be older, it is likely that much of the evidence mentioned in the previous section is also relevant to them. It is probable that other unique factors need to be considered given the wide range of impairments, possible combinations of these and the deterioration over time seen in individuals with Parkinson's disease. Although there is good evidence for the positive effects of exercise for people with Parkinson's disease (Goodwin et al., 2008; Lima et al., 2013; Tomlinson et al., 2012), there is little information about what exercise means to people with Parkinson's disease and how specific factors influence exercise participation for this group. A small number of qualitative and quantitative studies have investigated these issues. The findings will be presented and discussed, however, the

strength of this evidence needs to be considered in light of the small number and quality of studies. A detailed summary of the qualitative studies is presented in Table 1.1.

In addition, despite the evidence for the benefits of exercise, people with Parkinson's disease are known to be 29% less active than age-matched controls, further supporting the need for understanding exercise behaviour in people with Parkinson's disease (van Nimwegen et al., 2011). In van Nimwegen's study disease severity, gait impairment and disability in daily living explained 23% of the variance suggesting motor impairments may influence physical activity behaviour. However, a large portion of the sedentary behaviour remained unexplained (van Nimwegen et al., 2011) suggesting that there are other yet to be identified influences on this behaviour.

**Table 1.1** Summary of qualitative studies investigating influences on exercise participation in people with Parkinson’s disease

Population		Design			Exercise program			Findings			
Author	Key inclusion criteria	N	Age ( <i>yr</i> )	Disease duration ( <i>yr</i> )	Research questions	Method of analysis	Data collection	Dose (Frequency, Duration)	Delivery (Location, Method, Supervision)	Results	*Comments on quality
Ene et al (2012)	PD, H&Y 1-3, Participation in exercise program as part of a RCT, independent walking, no "on" freezing, MMSE $\geq 24$	18	Mean (SD) 70 (11)	Not stated	To learn more about the current exercise attitudes and behaviours of the graduates and those who had enrolled but not completed the study	Responses clustered according to content and frequencies reported	Structured interviews by psychology graduates (3 hours of education related to PD) under supervision of investigator	3-7 x week 16 months	Experimental groups: aerobic exercise; flexibility, balance and function exercises - gradually reducing supervision in group setting over 16 months Control: home-based exercise plus monthly supervised group sessions	There was a decline in activity levels after cessation of the program Motivators: Exercise might help control PD related problems Health and psychological benefits Recommendation of physician Individualisation of programs Barriers: PD and non-PD related health problems Travel time Lack of time	Structured interviews and method of data analysis (which is not clear) provides a thin description of issues. No reported attention given to issues of credibility. Little interpretation of results but identified issues to be explored in further studies.
Eriksson et al (2013)	PD H&Y 1-4, Regular participation in a centre-based exercise program for at least 12 months, Independent walking with or without an aid	11	Mean (range) 74 (61-81)	Mean (range) 9 (2-17)	To explore and generate an understanding of the meaning of physical exercise in the lives of individuals with PD participating in the exercise program	Grounded theory. Manual and computer analysis (OpenCode). Coding, constant comparison, memo-writing. Researcher triangulation and member checking used.	In-depth, semi-structured interviews recorded and transcribed.	1 x week $\geq 12$ months,	Centre-based, group aerobic or circuit class, full-supervision.	Core category "Keep moving to maintain the healthy self" Other categories: Having explicit life goals, confidence in one's own ability, taking rational position, exercising to slow progress, exercise to achieve well being, exercise as coping strategy	Design and data analysis appropriate means of answering question. Credibility well considered, however, the interviewer was one of exercise leaders. Interactions of the main themes interpreted in a model explaining uptake and adherence to exercise
O'Brien et al (2008)	PD H&Y 1-4, completed participation in	13	Mean (SD) 68 (7)	Mean (range) (0.3-16)	Explore the positive and negative aspects and outcomes of a PRE program for adults with PD	Phenomenological framework, Grounded theory methodology,	Semi-structured, in-depth interviews	3 x week 10 weeks	Centre-based, group, strengthening exercises,	i) Motivators for participation were broader than physical outcomes ii) Outcomes were broader	Appropriate design and detailed data analysis. Attention given to

Population				Design			Exercise program			Findings	
Author	Key inclusion criteria	N	Age (yr)	Disease duration (yr)	Research questions	Method of analysis	Data collection	Dose (Frequency, Duration)	Delivery (Location, Method, Supervision)	Results	*Comments on quality
	exercise program as part of a RCT, age > 40, walk independently			months	and to identify motivators and barriers to begin and continue with PRE program.	computer aided analysis (NVivo), researcher triangulation	that were recorded and transcribed, Visual analogue scale		2 x week. Home-based, unsupervised, strengthening exercises, 1 x week	than physical outcomes iii) Indicators of success varied iv) Participant's experience was positive	credibility issues. Valuable early findings specific to successful participation in a strengthening program.
Quinn et al (2010)	PD or HD – early to mid-stage disease  PTs - more than 2 yrs experience working in senior or supervisory role with patients with long-term neurological conditions	5 PD  5 HD  8 PT	PD Range 50-60 HD Range 41-79	PD Range 1-9, HD Range 2-16	1. What are client's views about independent exercise programs? 2. What are therapist's views on prescribing such programs? 3. What is the impact of disease-specific and non-disease specific issues on the design and implementation of such programs? 4. What factors do therapists consider important when designing independent programs?	Grounded theory, computer aided analysis (NVivo & QSR), researcher triangulation, member & peer checking for focus groups	Interviews using open-ended questions with HD and PD people Focus group with PTs	Variable – not all participants were engaged in a regular exercise program	Not stated	Over-riding theme was that engaging in an exercise program was considered beneficial for managing the symptoms related to movement disorders. Barriers were – disease specific limitations, safety (only physiotherapists) and program location. Motivators were understanding the relevance of the exercises	Robust design and credibility. Findings of value for a specific group of people with early PD and HD
Ravenek and Schneider (2009)	PD H&Y 1-2 Age 45-60	7	Range 51-59	Range (1-7)	Explore the perceived types of social support and how this support interacts with perceptions of control in early PD	Phenomenology, Interviews transcribed & personal information removed from transcripts, manual coding, data & researcher triangulation	Bk/ground quest/aire & semi-structured interviews	Active in community based physical activity and previously participated in exercise programs at the research centre	Community	Three different types of social support were identified in the study (instrumental, informational and emotional). An interaction was observed between the support for physical activity provided by specific groups of people and the participant's perceived control over PD through exercise.	Design appropriate. Some attention given to credibility issues. Findings linked with model of physical activity behaviour. Findings of value to people with early onset, early stage PD

PD=Parkinson's disease; HD=Huntington's disease; PT=physiotherapist; PRE = Progressive resisted exercise; H&Y= Hoehn and Yahr rating scale (Hoehn & Yahr, 1967); RCT=randomized controlled trial;

\* Comments on quality follow the Qualitative Research Checklist from the Critical Skills Appraisal Programme (CASP) at <http://www.casp-uk.net>, accessed 15<sup>th</sup> January 2014

### *Self-efficacy*

Self-efficacy beliefs have been associated with exercise participation in older people and people with chronic disease and have also been associated with exercise participation in people with Parkinson's disease. In a study investigating exercise behaviour in people with mild-severe Parkinson's disease (Hoehn & Yahr stages 1-4), participants with high self-efficacy for exercise were found to be more than twice as likely to exercise as those with low self-efficacy (Ellis et al., 2011). Confidence in ones' own ability to participate in exercise, which is the essence of self-efficacy, was identified as a main motivating factor in a qualitative study investigating the meaning of physical exercise in the lives of people with Parkinson's disease currently involved in exercise (Eriksson et al., 2013). In this study factors which impacted on self-efficacy for exercise were whether or not a person had an identity of being physically active and their ability to adapt activities to accommodate disability (Eriksson et al., 2013). Identity is the way an individual defines themselves and differentiates themselves from others (Charmaz, 1995). Adapting activities to account for disability in order to maintain identity is a component of adjustment to having a chronic disease (Charmaz, 1995) and this is the first study to identify and link these factors to self-efficacy beliefs in people with Parkinson's disease.

### *Belief in the benefits of exercise for Parkinson's disease*

Echoing the evidence in people with chronic disease and disability, belief in exercise as a means of exerting control over the disease by slowing progression and maintaining independence, is identified as a strong motivating factor for exercise participation in people with Parkinson's disease (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Quinn et al., 2010; Ravenek & Schneider, 2009). Again some people held the belief so strongly that they felt they had no choice but to exercise to manage the disease

(Ravenek & Schneider, 2009). In all but one of these studies the participants who held the belief were currently participating in exercise. Although the conflicting scenario, that is, that some who held this belief were not exercising was evident in another study, this conflict was not explored (Quinn et al., 2010).

### *Outcome expectations and realisations*

In Bandura's psychosocial model, outcome expectations are one of the key determinants of health behaviour. This is identified as important in people with Parkinson's disease through their strong belief in exercise to manage the disease. Low outcome expectations have been associated with non-exercisers with Parkinson's disease (Ellis et al., 2013). In addition, the outcome of exercise participation also appears important for continuing exercise participation. While participants in Parkinson's disease exercise programs identified improvements in physical ability and activity levels as important motivating factors they also identified improvements in other areas that were equally, if not more, motivating (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008). In one study several participants felt they had not improved physically but kept exercising because of the social interaction gained through exercising with others (O'Brien et al., 2008). Other valued, motivating outcomes that were identified included: a feeling of well-being, being more alert, feeling socially connected and increased appetite (Eriksson et al., 2013; O'Brien et al., 2008).

### *Social support*

Social support, consisting of support from others with the disease as well as those without, has been identified as a motivating factor to exercise participation in people with

Parkinson's disease (O'Brien et al., 2008; Ravenek & Schneider, 2009). Participants in a Parkinson's-specific exercise program valued the sharing of information about the disease with others in the group and the reduced social isolation derived from realising they were not alone (O'Brien et al., 2008). Ravenek and Schneider (2009) investigated the impact of social support on exercise participation in people with early Parkinson's disease (Hoehn & Yahr 1-2) (Ravenek & Schneider, 2009). They found that social support was a motivating factor and also identified a positive interaction between perceived support and perceived control over the disease. They postulated that social support influenced exercise participation by mediating perceived control over the disease (Ravenek & Schneider, 2009). Ravenek classified support as instrumental (actions carried out by others to assist exercise participation such as providing transport), informational (education and knowledge) and emotional (encouragement) and all three types of support were identified as motivating influences. Family, friends and work colleagues tended to provide instrumental and emotional support whereas allied health practitioners were the main source of informational support (Ravenek & Schneider, 2009). It is probable, however, that the views expressed by participants in these studies are likely to have volunteer bias. They may not be representative of the Parkinson's disease population in general but only the portion of the population who offered to participate in studies involving exercising with others with Parkinson's disease.

#### *Health professional advice*

Consistent with research in older people and those with a chronic disease and disability, advice from a health professional about the benefits of exercise, how to exercise and what programs are available, has been identified as a motivating influence on exercise participation in people with Parkinson's disease (Ene et al., 2011; O'Brien et al., 2008;



Quinn et al., 2010). Conversely, lack of information about these issues has been identified as a barrier to exercise participation (Quinn et al., 2010; Ravenek & Schneider, 2009) and this applied mainly to lack of advice from a physician. This was thought to be due to lack of time during consultations rather than physicians' lack of belief about the efficacy of exercise (Ravenek & Schneider, 2009), as participants described how physicians encouraged them in their exercise participation once they were aware of their involvement, but they hadn't recommended it in the first place (Ravenek & Schneider, 2009). In all but one of the studies discussing advice from a health professional, participants were already participating in exercise and the importance of health professional advice for people with Parkinson's disease who were not exercising was not investigated.

#### *Type of exercise program*

To date there has been little investigation into the influence that the type of exercise program has on exercise participation in people with Parkinson's disease and the evidence supporting the effectiveness of exercise has generally been drawn from supervised group exercise programs. In a systematic review of 53 randomized control trials of exercise or motor training in people with Parkinson's disease 74% of them were fully supervised (Allen et al., 2012). This indicates that the evidence for exercise and motor training in people with Parkinson's disease, which is generally positive, has to a large extent been derived from trials involving a high-degree of supervision. Trials that have been effective in increasing strength (Dibble et al., 2006), power (Paul et al., 2013) and reduced the number of falls (Li et al., 2012) have been fully supervised and in a trial comparing the effectiveness of a home exercise program with a supervised program the supervised program was more effective (Dereli & Yaliman, 2010).

It may be that research involving supervised, group exercise programs has mostly attracted those people with Parkinson's disease who prefer to exercise in a supervised group situation. There is evidence that people with Parkinson's disease express a wide range of preferences, other than supervised group exercise, for exercise and physical activity participation (Abrantes et al., 2012; Quinn et al., 2010). The results of both these studies regarding exercise preference appear important as some of their participants were not involved in any formal exercise programs and had varying levels of physical activity. In Abrantes et al's (2012) study there was general agreement that the people preferred to exercise at a moderate intensity (76%), in the morning (73%), at scheduled times (69%), with others with Parkinson's disease (80%), in disease specific programs (91%) and have options for varied activity (73%) (Abrantes et al., 2012). However, on other preferences such as whether they preferred supervised or unsupervised programs and where the exercise or physical activity took place they were divided (Abrantes et al., 2012). Different preferences for exercise location and degree of supervision have also been reported in another study (Quinn et al., 2010). It does appear that people with Parkinson's disease have varying exercise preferences and mode of exercise program delivery may play an important role in uptake of programs in this population but this has not yet been explored.

#### *Health conditions other than Parkinson's disease*

The evidence is not clear on the impact of other health conditions on exercise behaviour in people with Parkinson's disease although there is data that confirms that comorbidities are common in these individuals (Temlett & Thompson, 2006). Health conditions other than Parkinson's disease have been found to make continuing exercise participation difficult in a long-term exercise program (Ene et al., 2011) and concurrent health problems have been identified as a potential barrier to continued exercise participation by participants in

another long-term program (Eriksson et al., 2013). Yet an investigation into the characteristics of exercisers and non-exercisers with Parkinson's disease found there were no differences in the number of co-morbidities in the exercisers and the non-exercisers (Ellis et al., 2011).

### *Transport*

Consistent with the findings regarding exercise participation in people with a chronic disease and disability, transport has been found to be an influence on exercise behaviour in people with Parkinson's disease. Lack of transport is mentioned as a barrier in several studies (Ene et al., 2011; Quinn et al., 2010; Ravenek & Schneider, 2009) and a potential barrier in one study (Eriksson et al., 2013). It is interesting that this was identified in two studies that investigated people with early stage Parkinson's disease (Quinn et al., 2010; Ravenek & Schneider, 2009) because lack of transport might not be expected to be a barrier for people in the early stages of the disease.

### *Time*

As in older people, lack of time has been identified as a barrier to exercise participation in people with Parkinson's disease (Ellis et al., 2013; Ene et al., 2011). In a study comparing non-exercisers with exercisers, the non-exercise group were three times as likely to blame lack of time for lack of exercise participation as the exercise group and this was irrespective of disease severity (Ellis et al., 2013). Interestingly some people in the exercise group also perceived lack of time as a barrier to exercise participation. The authors suggested that self-efficacy is a likely explanation for this because people with high self-efficacy for exercise are more likely to find time to exercise, that is, they prioritise exercise in the presence of perceived barriers (Ellis et al., 2013).

### *Environment*

There is little evidence about the impact of the physical environment in influencing physical activity and exercise behaviour in individuals with Parkinson's disease but a qualitative study looking at community walking identified aspects of the environment that were perceived as barriers to walking outside the home for individuals with Parkinson's disease (Lamont et al., 2012). These included uneven surfaces, slopes, slippery surfaces, travelators, wet weather and poor lighting. These factors were found to influence community walking in specific ways such as increasing fatigue, increasing fear of falling, increasing freezing of gait or preventing the individual from going out at all (Lamont et al., 2012). The findings from this study suggest that, although not well understood, it is likely that physical environmental factors may have an important role in influencing physical activity participation in people with Parkinson's disease.

### *Motor impairments*

The motor impairments of Parkinson's disease (bradykinesia, akinesia, rigidity and impaired balance) and the increase in severity of these over time could feasibly be barriers to sustained participation in exercise. The evidence, although limited, does not appear to support this premise unreservedly. Impairments, activity limitations, participation restrictions or disease severity were not associated with exercise behavior in two cross-sectional studies by Ellis comparing exercisers with non-exercisers (Ellis et al., 2013; Ellis et al., 2011). In studies investigating attitudes towards exercise in individuals with mild to moderate Parkinson's disease almost all participants did not feel that the disease affected their ability to exercise (Abrantes et al., 2012; Quinn et al., 2010). Increasing impairment and fear of falling, however, were associated with reduced confidence in ability to exercise (Eriksson et al., 2013) and fear of falling was associated with non-exercise behaviour in people with Parkinson's disease (Ellis et al., 2013) suggesting that some, but not all motor

impairments may exert some influence on exercise participation. It is important to note that fear of falling is complex and may reflect anxiety which is not consistently related to level of motor impairment.

Difficulty with motor learning is another motor impairment associated with Parkinson's disease that could potentially impact on exercise participation by reducing mastery experiences which in turn negatively impacts on self-efficacy (Bandura, 1998). The basal ganglia, which is involved in motor learning, is affected by the disease process of Parkinson's disease, resulting in slower and less efficient motor task acquisition and preservation than in controls (Nieuwboer et al., 2009). This could be explained by a reduction in implicit motor learning observed in people with Parkinson's disease (Siegert et al., 2006). Motor learning occurs via explicit and implicit means (Frensch, 1998). Explicit learning is learning which occurs with a high degree of awareness on the part of the learner such as with use of external cues and verbalisation while implicit learning is demonstrated in skills that are so automated that the learner has difficulty providing verbal explanations of the skill (Siegert et al., 2006). Although it is difficult to distinguish in practice between these two types of learning it would seem that people with Parkinson's disease may need to rely on explicit learning to replace their impaired implicit learning (Nieuwboer et al., 2009). This is supported by evidence that using external cues enhances motor task performance in people with Parkinson's disease (Nieuwboer et al., 2009). Difficulty in mastering new exercises that rely more on internally generated cues such as balance exercises and those that draw attention away from external cues such as dual task activities could potentially cause frustration and disappointment and lead to lack of perseverance with an exercise program.

### *Non-motor impairments*

It is only recently that attention has been directed towards the non-motor impairments of Parkinson's disease and the significant negative impact these symptoms have on an individual's health-related quality of life (Antonini et al., 2012; Duncan et al., 2013; Gallagher et al., 2010). Non-motor impairments are numerous (Figure 1.4) and common with 98% of people with Parkinson's disease reporting their presence (Barone et al., 2009) at an average of eight per person (Barone et al., 2009; Duncan et al., 2013; Khoo et al., 2013). They have been found to have a variable progression and increase in number over the course of the disease (Antonini et al., 2012). Quality of life is related to activity and participation and it may be hypothesised that the non-motor impairments of Parkinson's disease may have an equally, if not more, limiting impact on an individual's physical activity than the motor impairments of the disease. To date few studies have specifically investigated the relationship between non-motor impairments and physical activity in people with Parkinson's disease (Abrantes et al., 2012; Elbers et al., 2009; Garber & Friedman, 2003; Rochester et al., 2006). However, a number of non-motor impairments could potentially impact on exercise participation.

**Figure 1.4.** The non-motor symptom complex of Parkinson's disease derived from Chaudhuri (Chaudhuri et al., 2006)

**Neuropsychiatric symptoms**

Depression, apathy, anxiety  
Anhedonia  
Attention deficit  
Hallucinations, delusions, illusion  
Dementia  
Obsessional behaviour (usually drug induced), repetitive behaviour  
Confusion  
Delirium (may be drug induced)  
Panic attacks

**Sleep disorders**

Restless legs and periodic limb movements  
Rapid eye movement (REM) sleep behaviour disorder  
Non-REM sleep-related disorders  
Excessive daytime somnolence  
Vivid dreaming  
Insomnia  
Sleep-disordered breathing

**Autonomic symptoms**

Bladder disturbances (urgency, nocturia, frequency)  
Sweating  
Orthostatic hypotension (falls related to orthostatic hypotension, coat-hanger pain)  
Sexual dysfunction (hypersexuality - likely to be drug induced, erectile impotence)  
Dry eyes

**Gastrointestinal symptoms (overlaps with autonomic symptoms)**

Dribbling of saliva  
Ageusia  
Dysphagia and choking  
Reflux, vomiting  
Nausea  
Constipation  
Unsatisfactory voiding of bowel  
Faecal incontinence

**Sensory symptoms**

Pain  
Paraesthesia  
Olfactory disturbance

**Other symptoms**

Fatigue  
Diplopia  
Blurred vision  
Seborrhoea  
Weight loss  
Weight gain (possibly drug induced)

Depression is a common non-motor impairment of Parkinson's disease affecting 10-45% of the population (Chaudhuri et al., 2006) and has the greatest association with reduced quality of life (Antonini et al., 2012; Barone et al., 2009; Duncan et al., 2013), even in people in the very early stage of the disease (Muller et al., 2013). Depression has been associated with reduced physical activity in people with Parkinson's disease (Abrantes et al., 2012) and depressive symptoms have also found to be associated with reduced self-efficacy in older adults (Davis-Berman, 1990; Paxton et al., 2010). These relationships suggest that depression may be associated with an individual's ability to participate in physical activity and exercise by its presence and its relationship with self-efficacy. Linked with depression is anhedonia, a problem experiencing pleasure from normally pleasurable activities, which is another non-motor impairment of Parkinson's disease (Chaudhuri et al., 2006). If the outcome realisation of exercise is not enjoyable, exercise participation is likely to be difficult to sustain.

Apathy is defined as a loss of motivation resulting in reduced goal directed behaviour (Richard, 2007) and has also been associated with reduced levels of physical activity in people with Parkinson's disease (Abrantes et al., 2012). Apathy is recognised as a distinct non-motor impairment of Parkinson's disease with a prevalence of around 30% (Pluck & Brown, 2002; Starkstein, 2012). It has a strong association with depression and dementia and if people with dementia and depression are excluded from people diagnosed with apathy its prevalence tends to be lower at 5-10% (Starkstein, 2012). The mechanisms underlying the association of apathy with Parkinson's disease are not well understood but it is thought that it could be the result of neuronal degeneration in the reward centers of the brain or disruptions in neuronal pathways other than the dopaminergic ones (Chaudhuri et al., 2006). Apathy has been found to be one of the major determinants of reduced health-



related quality of life in people with Parkinson's disease (Antonini et al., 2012; Barone et al., 2009), including those recently diagnosed (Benito-Leon et al., 2012), and has been associated with reduced resilience (Robottom et al., 2012).

Pain that is not related to osteoarthritis, neuropathy or other causes of pain common in older people is another non-motor impairment of Parkinson's disease (Wallace & Chaudhuri, 2013) that could potentially influence participation in exercise. In a large survey of over 1,000 participants, leg pain was one of the most commonly reported non-motor impairments (Barone et al., 2009) and pain was rated in the top five most troublesome symptoms by people with early and advanced disease (Politis et al., 2010). This pain can be related to dystonia and motor fluctuations (Chaudhuri et al., 2006) or may be the result of abnormal central nociceptive input processing and involvement of peripheral pain receptors (Conte et al., 2013; Defazio et al., 2013). People with Parkinson's disease may also have pain from secondary impairments such as contracture due to rigidity (Defazio et al., 2013).

Another non-motor impairment involving a disorder of sensorimotor integration is impaired proprioception (Conte et al., 2013; Maschke et al.; Zia et al., 2000) and this is likely to be a consequence of the dopaminergic denervation of the basal ganglia (Conte et al., 2013). It is known that sensory input, including proprioception, is essential for motor learning (Vidoni et al., 2010) and this along with difficulties with motor learning already mentioned could make exercise participation problematic for people with Parkinson's disease through reducing mastery of motor performance, especially in situations where supervision is minimal.

Cognitive impairment, especially impaired memory, attention and executive function is another common non-motor impairment (Barone et al., 2009), even in people with newly diagnosed Parkinson's disease (Duncan et al., 2013; Khoo et al., 2013; Muslimovic et al., 2005) and may also affect a person's ability to carry out an exercise program, especially if it is not fully-supervised. Even though impaired cognition is common and has been associated with reduced quality of life (Duncan et al., 2013), people with Parkinson's disease rated memory difficulties low in a ranking of the most troublesome symptoms (Politis et al., 2010). Physiotherapists identified cognitive function as a barrier to exercise participation in a study investigating attitudes towards exercise in people with early Parkinson's disease; however, difficulty concentrating was the only aspect of cognitive function identified as a barrier by the people with Parkinson's disease in the same study (Quinn et al., 2010). In this study the physiotherapists reported that they felt impaired memory contributed to the observation that clients frequently forgot to do their exercises and that impaired judgement raised safety concerns, in particular when prescribing challenging balance activities to be performed as part of a home exercise program (Quinn et al., 2010). In addition both physiotherapists and people with PD identified difficulty processing complex instructions as a barrier to exercise and advocated breaking down complex exercises into simple tasks (Quinn et al., 2010).

Fatigue is another recently identified and commonly reported non-motor impairment that could potentially be a significant barrier to exercise participation and there is some evidence to support this (Abrantes et al., 2012; Elbers et al., 2009; Garber & Friedman, 2003). Fatigue in Parkinson's disease is common (33-70%) (Friedman et al., 2011), occurs

early in the disease (Muslimovic et al., 2005), increases as the disease progresses (Friedman & Friedman, 2001) and is described by people with the disease as a troublesome symptom (Friedman & Friedman, 2001; Politis et al., 2010). Fatigue is associated with reduced health-related quality of life (Antonini et al., 2012; Elbers et al., 2013; Gallagher et al., 2010; Muller et al., 2013) and like apathy it is strongly associated with depression and anxiety (Elbers et al., 2013; Friedman et al., 2011). Fatigue is a complex issue in Parkinson's disease and is also associated with sleep disturbances (Wen et al., 2012; Beiske et al., 2010). Fatigue likely incorporates both central and peripheral components. Central fatigue presents as an overwhelming sense of tiredness (Friedman et al., 2011; Krupp & Pollina, 1996; Olsson et al., 2013) and peripheral fatigue refers to reduced muscle strength in response to repeated muscle use (Ziv et al., 1998). People with Parkinson's disease describe fatigue in both these ways. In a qualitative study looking at the meaning of fatigue in women with Parkinson's disease the participants felt their fatigue was different from that they had experienced prior to the onset of the disease and they described it as a feeling of total body inertia (Olsson et al., 2013). Fatigue was described much more specifically in a study examining community mobility in people with Parkinson's disease where participants described feeling weaker in specific muscle groups in response to walking for longer than usual (Lamont et al., 2012). An inverse relationship has been found between level of fatigue and level of physical activity in people with Parkinson's disease (Abrantes et al., 2012; Elbers et al., 2013) and participants in the study by Olsson et al. (2013) described aspects of fatigue that could partly explain this relationship. They described their fatigue as inescapable, variable in intensity, unpredictable, resulting in reduced energy and that it did not always respond to rest (Olsson et al., 2013).

In summary, even though exercise has been shown to be beneficial in the management of Parkinson's disease a large proportion of the population remain sedentary. Although there is general agreement on motivating influences and barriers to exercise and physical activity participation in people with Parkinson's disease there are limitations to the current qualitative evidence. The existing studies are of varying quality having utilised methodologies ranging from in-depth and semi-structured interviews with thematic analysis (Eriksson et al., 2013; O'Brien et al., 2008; Quinn et al., 2010; Ravenek & Schneider, 2009) to structured interviews generating a frequency list (Ene et al., 2011) (Table 1.1). In addition most studies have included participants who have successfully undertaken formal fully-supervised exercise programs (Eriksson et al., 2013) and/or are routinely participating in regular exercise (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009). This means there is a lack of evidence about influences on participation in minimally supervised programs. Given the recommendation for participation in ongoing exercise in Parkinson's disease and the cost of supervision, information on factors influencing participation in minimally supervised programs would seem necessary to help design appropriate and cost-effective programs. There is also very limited knowledge of factors influencing exercise participation in people with Parkinson's disease who did not successfully complete exercise programs. Information from these people would also appear essential to allow design of programs to include those whose needs may not be being met by existing programs.

It is also notable that with the exception of two studies (Eriksson et al., 2013; Ravenek & Schneider, 2009), explanatory models have not been developed to explain how the identified motivator and barrier issues interact and influence behaviour. Without this

understanding, it is doubtful if attending to the identified influences as separate entities will result in truly effective exercise program implementation for this population.

In addition, it would seem important to understand the meaning of the exercise experience in the lives of individuals with Parkinson's disease in order to strengthen and develop the implementation of effective exercise programs for this population, as it is only by understanding how people create their own reality that researcher begins to understand why they act as they do (Charmaz, 2006). Meaning is a pre-cursor to motivation and provides energy and direction to behaviour (Eriksson et al., 2013). Understanding the feelings, beliefs and thoughts that people with Parkinson's disease have towards exercise could potentially provide insights into their motivational basis for exercise participation. Only one study to date has broadly explored the meaning of exercise in people with Parkinson's disease (Eriksson et al., 2013). In this study, Eriksson and colleagues used grounded theory methodology and semi-structured interviews to obtain data from a subset of individuals with Parkinson's disease who were enrolled in a weekly exercise group. Only those 11 individuals who regularly participated for more than one year were included. They developed a model to explain the meaning of exercise, with an overarching theme entitled "keep moving to retain the healthy self", with two subthemes representing pre-requisites for adherence to physical exercise ("having confidence in one's own ability", "having explicit life goals") and four subthemes important for starting and maintaining exercise ("taking a rational position", "exercising to slow progression", "exercising to achieve well-being", "using exercise as a coping strategy").

Although findings from previous qualitative studies (Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009) are applicable to clinical practice, the cohorts

investigated were selected for success and arguably do not represent the full range of individuals with Parkinson's disease who present to physiotherapists for exercise intervention. The meaning of exercise and factors which affect motivation and decision making with respect to undertaking regular exercise in a group of individuals, who are variably successful in maintaining exercise in minimally-supervised programs, have not yet been fully explored.

The purpose of this study is to explore the experience of individuals with Parkinson's disease enrolled in a minimally-supervised exercise program, regardless of whether they completed the prescribed exercise or not. The participants were people with Parkinson's disease who had been part of a randomized controlled trial investigating the effect of a 6-month minimally supervised exercise program for falls prevention (Canning et al., 2009). By gaining a better understanding of the meaning of this exercise experience for the participants and the motivational processes that underpinned their exercise behaviour it is hoped that improved implementation of effective and sustainable exercise programs for people with Parkinson's disease will occur.

## **RESEARCH QUESTIONS**

The specific research questions for this study were:

1. What is the meaning of exercise for individuals with Parkinson's disease who have been variously successful in a 6-month, minimally supervised exercise program?
2. How do factors interact and influence decisions made about exercise participation by people with Parkinson's disease?

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## **CHAPTER 2: METHOD**

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## **DESIGN**

### **Choosing a research methodology**

The research questions for this study guided the choice of research methodology. The first question explored the meaning of exercise for people with Parkinson's disease while the second involved understanding the process of decision making with regard to exercise participation. Qualitative research is focused on understanding processes and meanings, both of which were issues I planned to explore in this study, whereas quantitative research focuses on causal relationships between variables (Denzin & Lincoln, 1994). Rather than hypothesise about causal relationships I aimed to develop ideas about the meanings constructed by and the behaviour of people with Parkinson's disease.

Next I needed to identify a model, or the philosophical stance, that made sense in reference to the research questions (Silverman, 2010). An interpretivist, constructionist framework was chosen because it provided a compatible framework for investigating the issues being examined. An interpretivist approach views any theory as an interpretation of the studied world and not an exact picture of it (Charmaz, 2006) and a constructivist model suggests that people create their own individual reality through their experiences and interactions (Charmaz, 2006). It is proposed that only by understanding how people construct meanings and actions can the researcher work out why they act as they do (Charmaz, 2006; Silverman, 2010). I therefore carried out an in-depth exploration of the exercise experience of a small group of people with Parkinson's disease to understand their construct of exercise and how they made decisions about continuing exercise participation. As I aimed to investigate how the participants create their individual reality through their experiences and interactions this fits neatly into the interpretivist, constructivist model.

The next step was to choose a specific qualitative research methodology that was congruent with the interpretivist, constructivist framework. After research and guidance I chose to use grounded theory. I will outline what grounded theory is and its historical development in order to explain why I chose to use a particular variant of this methodology. Grounded theory is a methodology that develops theory to explain phenomena from the collected data or “the ground”. It involves a back and forth approach comprising of collecting data, analyzing it and developing theory, then going back to collect data, analyze it and confirm or adjust the theory until the theory explains all the data (Cresswell, 2007). This methodology has changed and developed since it was first described by Glaser and Strauss in 1967 (Glaser & Strauss, 1967) in response to criticism of qualitative research practices as being anecdotal, unsystematic and biased (Charmaz, 2006). In addressing this criticism Glaser and Strauss’s approach was to move away from purely descriptive and reflective approaches and they developed a way of investigating and theorising about social processes which involved specifying explicit research strategies (Charmaz, 2006). Their approach to data analysis was systematic and prescribed as a way of incorporating scientific process into qualitative research (Cresswell, 2007). Glaser had a strong background in quantitative research and this can be seen in his strict coding methods and particular language that mirrors that used in quantitative methods (Charmaz, 2006).

In the 1990s Strauss and Corbin took grounded theory in a different direction, focusing particularly on investigating one core concept or process but still using prescribed systematic and analytic procedures (Strauss & Corbin, 1990). These procedures involved



looking at the data and breaking it into conceptual concepts known as a coding category. The researcher then chooses one category to focus on and develops other prescribed categories around this “core phenomenon”. The prescribed categories include causal conditions, strategies, intervening conditions and consequences (Cresswell, 2007). The researcher then develops hypotheses that interrelate the categories and finally develops a “conditional matrix” which is a device to assist the researcher to look at macro and micro conditions influencing the core category (Cresswell, 2007).

Ironically, by the 1990s grounded theory as described by Strauss, Glaser and Corbin was known for its positivistic assumptions (Charmaz, 2006). The positivist model of looking at reality assumes that there is only one version of the truth or reality, also being the theoretical underpinning of quantitative research. Concerned by this direction, other researchers began to move grounded theory away from this positivist approach to a constructivist approach. They did this by using the general principals of grounded theory in a less prescribed way (Charmaz, 2006). One such version of grounded theory is that described by Charmaz (Charmaz, 2006). This form of grounded theory does not focus on one core phenomenon and is not as prescriptive regarding the process of data analysis. It utilises the constructivist perspective of multiple realities, acknowledges the researcher’s standpoint and focuses on the beliefs and experience of the individuals (Cresswell, 2007). As the grounded theory approach described by Charmaz (Charmaz, 2006) has firm constructivist underpinnings as opposed to the positivist view of Glaser, Strauss and Corbin, I chose this variant to use in this study. Although less prescriptive, a systematic approach to data analysis was used. This will be described in further detail in the Data Analysis section of this chapter.

## **Method**

Data was collected by conducting in-depth, semi-structured interviews. This form of data collection was chosen as a way of gaining access to the participants' experience of exercise broadly, as well as the specific exercise program, and their interpretation of these experiences (Charmaz, 2006), in line with the constructivist framework. Open-ended interview questions were developed to provide a general structure to the interviews; however, the intention to follow any other leads that emerged during the interview was present from the outset (Figure 2.1). This flexibility to follow new ideas and to add new concepts during the research process is one advantage of using qualitative research methods (Charmaz, 2006).

The interview questions were designed to gain information about each participant's experience in the specific exercise program (Questions 1-7, 10) and about each participant's experiences of exercise throughout their lives, especially before their diagnosis with Parkinson's disease (Question 8). A question was also included that asked about plans for exercising in the future (Question 9). The interview questions were designed to gather information related to the second research question regarding the influences on exercise participation, however, it was also the intention that by probing leads given in the answers to these questions (especially questions 3, 8 & 10) information about the meaning of exercise for each individual would be revealed. It was decided that this approach of gathering information about the individuals' history of exercise participation and plans for the future would be more effective in revealing meaning than including a question directly about the meaning of exercise.

**Figure 2.1.** Interview questions

1. Tell me about your experience with the exercise program.
2. How did you feel when you were included in the exercise group?
3. Tell me how you felt before the exercise started and what your expectations of it were.
4. Tell me about the things that helped you to keep going with the program.
5. Was there anything about the program that made it hard?
6. Were there any major kinds of interruptions to your exercises? Tell me about them.
7. Tell me about how successful you feel you were in doing the exercises?
8. Before you were diagnosed with Parkinson's disease what kind of things did you do to exercise?
9. I am interested to know what your plans are now for exercising.
10. If you were to recommend this program to someone else what would you tell him or her?

As interviews are interactive communications that reflect what interviewer and interviewees bring to the interview and the relationship constructed during it (Charmaz, 2006) I was aware of some potential difficulties, which if not addressed, could impact on the quality of the data obtained. One problem that could occur is that the participants would construct a narrative that they thought I, as a physiotherapist, wanted to hear. I aimed to minimise the risk that this would happen in order to collect data that reflected the participants' actual experience of the program and not the one they thought they should have. This was addressed in several ways. Firstly, I was not involved in the conduct of the

exercise trial and this was communicated to the participants prior to the interview. Therefore, I had no prior knowledge of or relationship with the participants except as that of interviewer. Secondly, I explicitly let the participants know that I was interested in their whole experience of the exercise program as a person living with Parkinson's disease, including their actions, thoughts and emotions. To follow this through in the interview I was aware of my physiotherapist viewpoint but allowed the participants to be the experts by giving them respect and an opportunity to tell their stories. Giving the participants the choice of interview venue was another way of allowing them to exert some control over the situation and feel at ease. All participants chose to have the interview take place in their homes. This choice of venue potentially reduced the relative difference in power and status between the participants and myself which is another consideration when conducting interviews (Charmaz, 2006).

### **Ethical considerations**

The Human Research Ethics Committee of the University of Sydney (HREC) granted ethics for this project in July 2010 (Project no. 12976). The following ethical issues were considered: recruitment, confidentiality, safety and feedback to the participants.

Documents relating to these issues are located in Appendix 1.

### **PARTICIPANTS**

Participants were a sub-set of individuals who had completed (within the previous two months) the 6-month exercise arm of a falls prevention trial (Canning et al., 2009).

Inclusion criteria for the trial was a diagnosis of Parkinson's disease, aged 40 years or older, able to walk independently with or without a walking frame, have fallen in the past

year or having been assessed as being at risk of falling and have adapted to current anti-Parkinsonian medication for at least two weeks. Exclusion criteria were a Mini Mental State Examination score < 24, unstable cardiovascular disease or any other unstable chronic conditions that would interfere with the safety and conduct of the training and testing protocol (Canning et al., 2009). The program involved exercising three times a week at home and once a month in a group under supervision of a physiotherapist. Strengthening exercises, balance exercises and cueing strategies were included. Participants were recruited from two different trial locations: one metropolitan and one regional, chosen pragmatically based on timing of completion of the program and geographical accessibility for the interviewer. All eight individuals who were eligible for inclusion in this study chose to participate. This purposeful sampling was used to maximise the possibility of collecting rich data as each participant's experience would be recent and experiences from two different settings would be obtained. The sample included participants who had completed the 6-month exercise program as well as those who were unable to complete the exercise program. This purposive sampling, using different cases, allowed for testing of theories (Silverman, 2010). If a theory applies to cases where exercise participation is continuous as well as when it is interrupted or stopped it has greater strength (Silverman, 2010).

## **DATA COLLECTION**

### **Interviews**

The interviews took place in participants' homes between October and December 2010. The interviews ranged in length from 25 to 50 minutes. All participants gave written consent for the interviews to be recorded.

As I had no prior relationship with the participants it was important for some rapport to be built prior to the interview. Before the interview I had two phone conversations with each participant, one to see if they wished to be involved and to arrange an interview time and another a day before the interview to check that the time was still suitable. During these phone calls I allowed conversation to occur if the participant wished. By doing this I received some background information. For example, participant 1 spent some time telling me about medical conditions that had interrupted his exercise program and were still causing difficulties and participant 2 told me of some emotional stress she was going through with the divorce of her son. Prior to the interview some time was spent in general conversation with the participant. This meant some rapport had been developed by the time the interview took place.

One of the characteristics of grounded theory interviewing is that it should be flexible so that new ideas and leads can be followed. Although this can seemingly diverge from the initial interview main themes its aim is to correct tendencies to bring pre-conceived notions about what is happening and to refine the data collection to bring focus to an idea or theme (Charmaz, 2006). This occurred during my data collection. Initially I was focused on exploring characteristics of the exercise program that may have influenced exercise participation, such as the type and quantity of exercises, but within the first few interviews I became aware that participants were telling me that other factors were more important to them so these issues were explored in more depth in subsequent interviews. The interviews were listened to several times and were then transcribed verbatim using the conventions outlined by Browne (Browne, 2004).

## **Sampling**

Sampling for grounded theory interviewing is an ongoing process with initial sampling, a starting point followed by theoretical sampling which obtains more data to help clarify concepts (Charmaz, 2006). This means additional participants may be added as emerging themes or areas of investigation require (Holstein & Gubrium, 1995). The three participants initially interviewed had all battled significant barriers during their participation in the 6-month exercise program and as a result were not able to complete it, so I decided to check whether people who had successfully completed the program faced similar barriers and investigate how they successfully negotiated these. This was to test my emerging theories about factors involved in decision making about exercise. I was able to interview two participants who had successfully completed the exercise program. This is known as contrary case analysis and may be considered a component of theoretical sampling (Silverman, 2010).

The time to stop gathering data is when data no longer “sparks theoretical insights, nor reveals new properties of your main theoretical categories” (Charmaz, 2006). After eight interviews I had developed the main themes and the interactions between them. At this stage I went back to all the interviews to check if the themes encompassed all the codes (categories of data) contained in the interviews to ensure there were no codes that did not fit with the themes, which would require further investigation. This review demonstrated that all codes were accounted for by the themes indicating that the eight interviews were sufficient to answer the research questions. If this had not been the case more participants could have been recruited from other trial locations.

## **DATA ANALYSIS**

*“As we learn how our research participants make sense of their experiences we begin to make analytic sense of their meanings and actions.”* (Charmaz, 2006, p11)

The interviews were analyzed using Grounded theory guided by Charmaz (Charmaz, 2006) and the process of analyzing the interview data is outlined below.

### **Coding**

Interview recordings were listened to and transcripts were read several times by the interviewer and then coded. Coding is the process of labelling data in order to sort and categorise it (Charmaz, 2006). Initial coding involves looking for actions in each section of the data (Charmaz, 2006). This initial analysis assists the planning of subsequent interviews (Charmaz, 2006). An example of this initial coding on interview excerpts where participants are talking about difficulties with motivation is provided in Figure 2.2.



**Figure 2.2.** Initial coding

<b>Transcript</b>	<b>Initial coding</b>
<p><i>Participant 1: A 75 yr old man who has had Parkinson's disease for 3 yrs</i></p> <p>Don't listen to the surface thoughts in your mind because you'll find that you might be bombarded with negative thoughts but they're not necessarily the ones you put into action (laughs). Just discipline your mind cause your mind's like your muscles the same as exercise, don't listen to surface thoughts or don't say "woe, woe, woe is me" just analyze it and see what you do come up with, a positive aspect of what you are trying to achieve.</p> <p>You'll get a thought that that you're restricted a lot with your movements and does anyone really care and those sort of negative thoughts will come, try to surface but if you make a positive effort to not to accept – you don't have to accept them and you don't have to get morbid or anything. You can stay on the right track if you know that your thoughts are not what you've got to follow necessarily.</p>	<p>Ignoring negative thoughts</p> <p>Describing intrusion of negative thoughts</p> <p>Describing response to negative thoughts</p> <p>Believing that the mind can fight negative thoughts with practice and discipline</p> <p>Rejecting self-pity as consequence of negative thoughts</p> <p>Countering negative thoughts with positive</p> <p>Describing content of negative thoughts as movement restriction caused by PD, feeling isolated, self pity</p> <p>Describing pervasiveness of negative thoughts</p> <p>Fighting negative thoughts</p> <p>Dismissing negative thoughts</p>
<p><i>Participant 3: A 65 yr old lady who has had Parkinson's disease for 11 years</i></p> <p>I didn't enjoy doing the exercises for some strange reason. I think it was, I think it's the Parkinson's that does that. It doesn't give you a</p>	<p>Not enjoying exercises</p> <p>Blaming disease for lack of enjoyment of exercise</p>

<p>nice sort of leap into doing things. You've got to battle with willpower all the time. It's all too hard. Everything's too hard for you and you've got to overcome that, I mean most people get it some time or other but this is a sort of a cloudy battle in your mind with the brain sort of ah saying. "You don't have to do this", "I don't want to do it".</p> <p>That's the hardest part I found.</p>	<p>Battling with willpower</p> <p>Feeling things require energy you don't have</p> <p>Trying to fight that hopeless feeling</p> <p>Scaling problem with willpower - worse than normal - connecting it with the disease</p>
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The next stage in data analysis in grounded theory is focused coding where the most useful initial codes are chosen to categorise the data. After looking closely at the initial coding and using trial and error I decided the most useful initial codes that covered larger chunks of data were "battling negative thoughts" and "linking the disease with loss" as seen in Figure 2.3.

**Figure 2.3.** Focused coding

<b>Transcript</b>	<b>Focused coding</b>
<p><i>Participant 1: A 75 yr old man who has had Parkinson's disease for 3 yrs</i></p> <p>Don't listen to the surface thoughts in your mind because you'll find that you might be bombarded with negative thoughts but there not necessarily the ones you put into action (laughs). Just discipline your mind cause your mind's like your muscles the same as exercise don't listen to</p>	<p>Battling negative thoughts</p>

<p>surface thoughts or don't say "woe, woe, woe is me" just analyze it and see what you do come up with a positive aspect of what you are trying to achieve.</p> <p>You'll get a thought that that you're restricted a lot with your movements and does anyone really care and those sort of negative thoughts will come, try to surface but if you make a positive effort to not to accept – you don't have to accept them and you don't have to get morbid or anything. You can stay on the right track if you know that your thoughts are not what you've got to follow necessarily.</p>	<p>Linking disease with loss</p> <p>Battling negative thoughts</p>
<p><b><i>Participant 3: A 65 yr old lady who has had Parkinson's disease for 11 years</i></b></p> <p>I didn't enjoy doing the exercises for some strange reason. I think it was, I think it's the Parkinson's that does that. It doesn't give you a nice sort of leap into doing things. You've got to battle with willpower all the time. It's all too hard. Everything's too hard for you and you've got to overcome that, I mean most people get it some time or other but this is a sort of a cloudy battle in your mind with the brain sort of ah saying. "You don't have to do this", "I don't want to do it".</p> <p>That's the hardest part I found.</p>	<p>Linking disease with loss</p> <p>Battling negative thoughts</p> <p>Linking disease with loss</p>

### **Memo writing and the constant comparative method**

Memo writing is the writing down of insights, emerging thoughts and concepts arising from engaging with the data (Charmaz, 2006) and is a way of recording the results of using the constant comparative method that is a distinct feature of grounded theory. The constant comparative method refers to the process of theory creation where the researcher compares data with other data (in the same interview and between interviews) and with codes and subthemes in order to understand the similarities and differences and clarify the relationship between these factors (Charmaz, 2006). Memo writing is done in an informal style, is similar to research notes and reflects and records the research process. See Figures 2.4 and 2.5 for examples of memos outlining possible theory written during data analysis. Figure 2.4 outlines concepts developed about the decision-making process regarding exercise participation early in the investigation (subsequent analysis revealed a more complex interaction of factors that is outlined in Chapter 4). Figure 2.5 is attempting to identify aspects of the code “exercise beliefs”.

**Figure 2.4.** Example of memo 1: Factors influencing decision making about exercise participation

Factors predisposing one to exercise	Factors providing a barrier to exercise
<ul style="list-style-type: none"> <li>• The program <i>fits in</i> with the person's core beliefs about exercise (exercise experience, persistence pays off, expect some difficulties, belief one can return to exercise after interruption)</li> <li>• Cognitive thinking (strategies to overcome negative thoughts)</li> <li>• <i>Fits in</i> with current priorities (exerting control) e.g. recognises benefits, participation</li> <li>• Program <i>meets need</i> for involvement/participation (involved in helping others with PD)</li> <li>• Program message <i>consistent</i> with other messages received and beliefs</li> <li>• Program message <i>fits in</i> with identity as a person with PD (group allows one to pass on coping tips, belief that one can help maintain abilities through exercise)</li> <li>• The program <i>fits in</i> with limitations imposed by PD (achievable, can fit in with variation of symptoms)</li> </ul>	<ul style="list-style-type: none"> <li>• The program does not fit in with the person's core beliefs about exercise <i>conflict</i> (exercise should be an activity rather than prescribed exercise, should not cause pain, no experience of returning to exercise after disruption)</li> <li>• Unsuccessful <i>battle</i> with negative thoughts (apathy)</li> <li>• <i>Conflicts</i> with current priorities (exerting control) e.g. illness, pain, tiredness</li> <li>• <i>Letting go</i> of involvement/participation in the program Disappointment at not being able to fulfil original commitment leads to a reluctance to commit again</li> <li>• Program message <i>conflicts</i> with other messages received and beliefs</li> <li>• Program message <i>conflicts</i> with identity as a person with PD (rejecting PD as part of identity, belief in inevitability of decline)</li> <li>• The program is <i>not achievable</i> with limitations imposed by PD (symptoms too variable, fatigue)</li> </ul>
<p>A person will give a different weighting to each of these factors each day and the weighing up of these factors is likely to be an ongoing and variable process.</p> <p>For the conditions to be optimum for exercise to occur all factors on the left hand side of the table should be present.</p> <p>When exercise does not occur it is likely to be due the presence of one or more of the factors on the right hand side of the table. It would seem possible that with more of these factors present the less likely it would be for exercise to occur i.e. exercise would assume a lower priority.</p>	

**Figure 2.5.** Example of memo 2: Beliefs about exercise

- All participants appeared to believe the concept that exercise is good. However this seemed to be a belief in a general concept and people evaluated the exercises for them individually in a more complex way. For example one participant said, “I never queried the value of the exercises”, however, she stopped doing the exercises because she thought they were causing her pain. So although she believed they had generic value the exercises were not of any value to her at that particular time.
- Participants believed also that exercise could maintain health and prevent deterioration. They believed exercise could help you “hold on to what you have”.
- A belief that doing something is better than nothing.
- Persistence brings rewards.
- Belief that exercise can cause pain, the thought that you need to be cautious.
- People evaluate their exercise experience in a context specific way. The outcome of this evaluation can form new beliefs or strengthen previously held beliefs. The evaluation may be directly related to the effects of the exercise or to the exercise experience more generally. For example whether they enjoyed doing the exercises, whether they understood the ideas behind the program or whether they achieved a sense of satisfaction from doing them.
- Some aspects of exercise were valued highly by the participants (understanding the idea behind the program, the progression of the exercises by the physiotherapist, feedback, exercising in a group).
- Belief that exercise should be fun.
- Belief that exercise should be challenging.
- Participants demonstrated a broad understanding of exercise to include physical activity such as household chores, singing, and playing bridge.
- Belief that sitting around and doing nothing is not good for you.
- Belief that you can do too much physical activity.
- The belief that you can’t do as much exercise as you get older was a common theme. People had certain expectations of what they should be able to do and did not wish to exceed this.
- The observation that by trying to remain active families don’t really understand what it is like to have Parkinson’s disease. The idea of “pretending things are normal”. “Closing the door”. This is where groups are important as everyone has Parkinson’s disease.

The initial analysis of each interview, consisting of line-by-line coding, focused coding and memos were reviewed by the other two investigators. During this review points of difference and similarity were discussed with the aim of reducing personal bias in a form of investigator triangulation (Searle, 1999). This collaborative review of the initial analysis proved important in several ways. It ensured my analysis was not selective in the data that was used, made me aware of some insights I was initially missing and ensured I stayed close to the data. The following example illustrates how this occurred.

Halfway through the project I was sure I had developed a very important code identified as exercise evaluation that referred to the participants evaluating individual exercises and either doing them, modifying them or omitting them according to their evaluation, much as a physiotherapist would do. After discussion with my co-investigators I realised I was focusing on the data with a physiotherapist's assumptions about exercises and as a result was missing what the participants were actually saying. I re-read the transcripts being more open to what participants were actually saying (staying close to the data) instead of selectively searching for the concepts that I was sensitised to as a physiotherapist. The result of this was that evaluation of the exercises remained a concept but was a small part of a much more important idea about people making sense of the whole exercise experience.

Using the constant comparative method between data and the codes the evolving codes were then grouped into categories or subthemes. As subthemes emerged the interview questions in subsequent interviews were altered to explore these further. For example, it became apparent in the initial interviews that altered motivation was a common problem so this issue was specifically explored in more detail with future participants.

Again, using the constant comparative method, the subthemes were grouped to form main themes and the interactions between these themes were considered to develop theory that would answer the research questions. It can be seen that the data analysis was not sequential, instead it involved going forwards and backwards between the different stages

(including data collection) as the data, codes, memos, themes and theory were compared and refined. The comparative method was also used to compare my emerging theories with other research in the area as a way of further developing and refining the theory.

## **QUALITATIVE RIGOUR**

### **Quality in qualitative research**

Ensuring quality in qualitative research using criteria is problematic because the concepts of validity and reliability that are used in quantitative research are focused on measurements associated with creating a single, stable truth and these are not a good fit for the study of meanings and processes that reveal multiple realities which occur in qualitative research. Qualitative researchers have grappled with issues of scientific rigour, and potential solutions have been proposed that have ranged from total rejection of the positivist requirement for quality to be addressed to the development of quality categories similar to those used in qualitative research (Searle, 1999). Some researchers claim that establishing trustworthiness is the comparable idea of establishing validity and reliability in quantitative research (Lincoln & Guba, 1985; Searle, 1999). To achieve trustworthiness the researcher must be able to consider the truth value, the applicability, the consistency and the neutrality of the research. Hammersley (1992) suggests that truth and relevance are the most important concepts to consider in achieving quality. Flexible criteria checklists for quality have been developed from this (Hammersley, 1992).

### **Quality in this research**

I chose to use processes identified by Silverman, Searle and Charmaz to ensure the quality of this work (Charmaz, 2006; Searle, 1999; Silverman, 2010). Searle states that intense



methodological awareness is an appropriate measure of quality that doesn't reject the positivist requirement for quality or subject qualitative research to strict rule following (Searle, 1999). Intense methodological awareness requires the researcher to understand the consequences of methodological decisions made during a research study and I believe this has been demonstrated in the methodological decision-making process undertaken before and during the research process outlined above.

Charmaz holds the view that depth and scope of the data is the start of quality in qualitative research (Charmaz, 2006). She states that entering the participants' worlds with respect and allowing them to be experts can assist in collecting quality data. In this study, careful consideration of the interview process prior to conducting the interviews, an attitude of respect for, and rapport with, the participants, allowed me to collect rich and substantial data.

Silverman asks the researcher to consider the representativeness of the research participants and proposes several methods to ensure the validity of the research (Silverman, 2010). He asks the researcher to reflect on what types of people were excluded and what types of people were over-represented. In this study the sampling frame was in the first instance determined by the inclusion/exclusion criteria of the randomized controlled trial (Canning et al., 2009). The protocol for this trial excluded people who could not walk independently with or without a walking frame, those who were not at risk of falling and those with cognitive impairment. This meant that the people included were representative of the ones most likely to be the targets of exercise intervention for falls prevention for people with Parkinson's disease, that is, those with mild-moderate disease

without cognitive impairment but who were at risk of falling. Also as the participants for this study were sourced from an exercise research trial they were most likely interested in exercise as a way of managing their disease. Five of the eight participants in this study had extensive involvement with organised exercise and sport well into middle age and all reported at least 90 minutes of habitual physical activity each week prior to participating in the research. Thus consideration of both these questions has implications for the results of this study and their applicability to other groups and these will be discussed further in Chapter 4.

Silverman also proposes ways of thinking critically about data analysis in order to achieve validity: the constant comparative method, comprehensive data treatment, deviant case analysis and using appropriate tabulations (Silverman, 2010). From the outset I intended to incorporate as many of these as possible during the process of my research. Validity was addressed by thinking and acting critically about data analysis in the ways described by Silverman during the course of the research. I employed the constant comparative method for data analysis returning constantly to the data ensuring that my treatment of the data was comprehensive and not selective. As described, deviant case analysis was addressed in the context of theoretical sampling to check my emerging theory about barriers in decision making by interviewing participants who had successfully completed the exercise program as well as those who had not. Tabulations refer to counting pieces of data in order to look at frequency of occurrence. This is a technique used in quantitative research so for tabulations to add validity to qualitative research they need to be done in the context of a theoretical rationale (Silverman, 2010). Although this was used sparingly I did go back to the data to count references to some subthemes in order to get an idea of their importance. For example, I decided to explore more closely the concept of the importance of feedback

in relationship to the participants making sense of the exercise experience. To be sure this was a relevant theme I first wanted to get an idea of how prevalent the concept was in the interviews so the number of times the importance of feedback was mentioned in each interview was counted. This gave information about how often it was mentioned across interviews as well as within them and the frequency convinced me to investigate this concept further. I then read the references to feedback for content and discovered it was a widespread and important idea. The use of tabulation initially ensured that this important part of the data was not missed and added to the comprehensive treatment of the data.

Another way of striving for quality in qualitative research is linking and comparing findings and theories critically with other research in the field. An initial literature review was undertaken prior to data collection and provided a list of factors known to influence exercise participation in people with Parkinson's disease along with several frameworks used to categorise these influences. This initial literature search revealed no information about the meaning of exercise in people with Parkinson's disease. Expectations and biases from the literature were accounted for by further literature reviews that occurred at different stages of the study. Literature was accessed during data collection to provide information about specific, unexpected factors, such as apathy, as they emerged from the interviews. Finally, a literature review was carried out after the analysis of the data accessing literature more widely to allow comparison of the theories developed from this study to others, especially in the field of adaptation to chronic disease. Also, by this stage, there were results available from one study that had investigated the meaning of exercise in people with Parkinson's disease that was also used to compare and link findings from this current study. A detailed linking and comparison of the literature with the findings from this study is undertaken in Chapter 4. In summary, this study was designed with

attention to quality standards for qualitative inquiry both in the design phase and throughout the research process.

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## **CHAPTER 3: RESULTS**

### **INTRODUCTION**

**MANUSCRIPT PREPARED FOR SUBMISSION TO *DISABILITY AND REHABILITATION***

### **CASE STUDIES ILLUSTRATING MAIN THEMES AND MODEL**

**Case study 1: Ann**

**Case study 2: Lon**

**Case study 3: Brian**

## **INTRODUCTION**

The findings of this study are presented in the form of a manuscript prepared for submission to *Disability and Rehabilitation*. In addition, three case studies will be presented providing examples of the main themes identified in the results, as well as illustrating the dynamic model developed to explain factors influencing decisions regarding exercise participation in people with Parkinson's disease. The reference style used in this chapter will be APA(6<sup>th</sup>) style to be consistent with the rest of the thesis but will be altered to CSE (Council of Science Editors) when submitted to *Disability and Rehabilitation* in order to comply with their requirements.

**MANUSCRIPT PREPARED FOR SUBMISSION TO *DISABILITY AND REHABILITATION***

**Title: Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson's disease: a qualitative enquiry**

**ABSTRACT**

**Purpose:** The aims of this study were to explore the meaning of exercise in people with Parkinson's disease who had undertaken a disease specific exercise program aimed at falls prevention and to examine factors influencing decisions about exercise participation.

**Method:** This was a qualitative study with data collected by in-depth semi-structured interviews and analysed using grounded theory methodology. The participants were eight older adults who had recently undertaken a 6-month, minimally-supervised physiotherapy falls prevention program for people with Parkinson's disease, regardless of whether they had completed the prescribed amount of exercise or not.

**Results:** Participation in a Parkinson's disease specific physiotherapy program involving group exercise provided an opportunity for participants to reframe their identity of their 'active' self. It was found that the decision to exercise or not was influenced by interactions between many changeable and dynamic factors. Three new influences on exercise participation were identified and explored: non-motor impairments of apathy and fatigue, the belief in a finite energy quota and the importance of feedback.

**Conclusion:** Complex and interacting issues, including non-motor impairments, need to be considered in order to enhance the development and implementation of effective exercise programs for people with Parkinson's disease.



## **Keywords**

Parkinson's disease, qualitative research, exercise therapy, physiotherapy, apathy, motivation, aged, feedback.

## **Implications for Rehabilitation**

- Exercise participation can assist individuals to reframe their identity as they are faced with losses associated with Parkinson's disease and ageing.
- Non-motor impairments of apathy and fatigue may influence exercise participation in people with Parkinson's disease.
- For people with Parkinson's disease feedback is important to decision making with respect to continuing exercise, therefore particular attention needs to be paid to the provision of feedback in exercise programs.

## **INTRODUCTION**

Parkinson's disease is the second most common degenerative neurological disease after Alzheimer's disease (Mellick, 2013). There is increasingly robust evidence acknowledging that both exercise and physiotherapy can improve mobility and health-related quality of life in people with Parkinson's disease (Goodwin et al., 2008; Tomlinson et al., 2012). This evidence informs health practitioners, such as physiotherapists, about the type of exercise that may increase or maintain mobility and provides impetus to deliver programs incorporating this knowledge. Less is known about how to implement exercise programs effectively to maximise participation, adherence and sustainability. Quantitative analysis shows that self-efficacy, rather than disability, is associated with regular exercise in people with Parkinson's disease and low outcome expectations regarding exercise is a barrier (Ellis et al., 2013; Ellis et al., 2011).

A small number of qualitative studies of varying quality have investigated motivating influences and barriers to exercise participation in people with Parkinson's disease using a variety of methodologies ranging from in-depth and semi-structured interviews using thematic analysis (Eriksson et al., 2013; O'Brien et al., 2008; Quinn et al., 2010; Ravenek & Schneider, 2009) to structured interviews generating a frequency list (Ene et al., 2011). Motivating influences identified include maintaining or increasing physical function (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008), slowing disease progression (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Quinn et al., 2010; Ravenek & Schneider, 2009), social support (Ene et al., 2011; Eriksson et al., 2013; Ravenek & Schneider, 2009), advice from health professionals (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009), exercising with others at a similar stage of the disease (O'Brien et al., 2008; Quinn et al., 2010), the psychological benefit of

exercise (Ene et al., 2011; Eriksson et al., 2013), having an individualised exercise program (Quinn et al., 2010) and having confidence in one's ability to exercise (Eriksson et al., 2013). Barriers to exercise participation identified included non-Parkinson's disease related health problems (Ene et al., 2011; Eriksson et al., 2013), Parkinson's disease related motor impairments (Quinn et al., 2010), problems with transportation (Ene et al., 2011; Eriksson et al., 2013), lack of knowledge about appropriate programs (Ene et al., 2011), lack of time (Ene et al., 2011) and lack of health professional advice about the benefits of exercise (Ene et al., 2011; Ravenek & Schneider, 2009). Although there is general agreement on influencing factors there are limitations to the current evidence in that most studies have included participants who have successfully undertaken formal fully-supervised exercise programs (Eriksson et al., 2013) and/or are routinely participating in regular exercise (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009).

Only two studies have gone beyond generating lists of motivators and barriers to exercise and developed explanatory models. Ravenek and Schneider (2009) undertook semi-structured interviews of seven people with early-onset, early-stage Parkinson's disease to specifically investigate how social support influences physical activity. They found that although social support does facilitate physical activity, this influence was mediated by participants' positive beliefs about the role of exercise in exerting some control over the disease. Only one study to date has broadly explored the meaning of exercise in people with Parkinson's disease (Eriksson et al., 2013). In this study, Eriksson and colleagues used grounded theory methodology and semi-structured interviews to obtain data from a subset of individuals with Parkinson's disease who were enrolled in a weekly exercise group. Only those 11 individuals who regularly participated for more than one year were

included. They developed a model to explain the meaning of exercise, with an overarching theme entitled “keep moving to retain the healthy self”, with two subthemes representing pre-requisites for adherence to physical exercise (“having confidence in one’s own ability”, “having explicit life goals”) and four subthemes important for starting and maintaining exercise (“taking a rational position”, “exercising to slow progression”, “exercising to achieve well-being”, “using exercise as a coping strategy”).

Although findings from previous studies (Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009) are applicable to clinical practice, the cohorts investigated were selected for success and arguably do not represent the full range of individuals with Parkinson’s disease who present to physiotherapists for exercise intervention. Factors which affect motivation and decision making with respect to undertaking regular exercise in a group of individuals, who are variably successful in maintaining exercise, have not yet been fully explored.

The aim of this study is to explore the experience of individuals enrolled in a minimally-supervised exercise program, regardless of whether they completed the prescribed exercise or not. The participants were people with Parkinson’s disease who had been part of a randomized controlled trial investigating the effect of a 6-month exercise program for falls prevention (Canning et al., 2009). By gaining a better understanding of the meaning of this exercise experience for the participants and the motivational processes that underpinned their exercise behaviour it is hoped that improved implementation of effective and sustainable exercise programs for people with Parkinson’s disease will occur.

## **RESEARCH QUESTIONS**

The specific research questions for this study were:

1. What is the meaning of exercise for individuals with Parkinson's disease who have been variously successful in a 6-month, minimally supervised exercise program?
2. How do factors interact and influence decisions made about exercise participation by people with Parkinson's disease?

## **METHOD**

### **Design**

Qualitative research methodology using an interpretivist, constructionist framework was utilised. This framework suggests that people create their own individual reality through their experiences and interactions (Charmaz, 2006). It is proposed that only by understanding how people construct meanings and actions can the researcher work out why they act as they do (Charmaz, 2006; Silverman, 2010). Eight in-depth, semi-structured interviews (Figure 1) ranging in length from 25 to 50 minutes were conducted in participants' homes. The interviewer (CO) had not been involved in the conduct of the exercise trial and had no prior knowledge of the participants. The interviews were recorded and then transcribed verbatim. The Human Research Ethics Committee of the University of Sydney approved the study. All participants gave written consent.

### **Participants**

Participants were a sub-set of individuals who had completed (within the previous two months) the 6-month exercise arm of a falls prevention trial (Canning et al 2009).

Eligibility criteria for the trial included: a diagnosis of idiopathic Parkinson's disease; age 40 years or over; ability to walk independently with or without a walking aid; stable anti-Parkinsonian medication for at least two weeks; one or more falls in the past year or

deemed to be at risk of falls based on physical assessment. Participants were excluded if they had a Mini-Mental State Examination score of less than 24, unstable cardiovascular disease, or other uncontrolled chronic conditions that would interfere with the safety and conduct of the training and testing protocol. The program involved exercising three times a week at home and once a month in a group under supervision of a physiotherapist.

Strengthening exercises, balance exercises and cueing strategies were included.

Participants agreed to continue their regular exercise regime while completing the trial.

Participants were recruited from two different trial locations: one metropolitan and one regional, chosen pragmatically based on timing of completion of the program and geographical accessibility for the interviewer. This purposeful sampling was used to maximise the possibility of collecting rich data as each participant's experience would be recent and experiences from two different settings would be obtained.

### **Data analysis**

The interviews were analyzed using grounded theory. This methodology involves systematically developing a theory by looking at data, developing ideas and then collecting more data that either confirms the theory or necessitates the development of a new theory (Charmaz, 2006). Data analysis occurred concurrently with data collection. Interview recordings were listened to and transcripts were read several times by the interviewer (CO) and then coded. Coding is the process of labelling data in order to sort and categorise it (Charmaz, 2006). Comparisons were made within and between interviews to ensure coding remained close to the data. The other two researchers (CC and LC) reviewed the initial analysis as a form of researcher triangulation and any points of difference were resolved through discussion. Memos and case studies were written to explain the emerging concepts and these concepts were then grouped into subthemes. As subthemes emerged the

interview questions in subsequent interviews were altered to explore these further. For example, it became apparent in the initial interviews that altered motivation was a common problem so later participants were questioned specifically about this. The subthemes were then grouped to form main themes. According to Charmaz (2006) the time to stop gathering data is when data no longer “sparks theoretical insights, nor reveals new properties of your main theoretical categories”. After eight interviews new themes were not emerging and a review of all interviews demonstrated that all codes were accounted for by the main themes indicating that this subset were adequate to answer the questions.

## **RESULTS**

All eight eligible participants from the two identified trial locations agreed to participate (Table 1). Three were from the regional group and five were from the metropolitan group. Seven lived with a spouse or other family members and one lived alone in a unit within an aged care complex.

Four main themes emerged from the data. These were adapting to change and loss, the influence of others, making sense of the exercise experience and hope for a more active future (Figure 2).

### **Adapting to change and loss**

All participants identified a variety of physical and mental changes attributable to both Parkinson’s disease and ageing that caused reduced ability to engage in physical activities and consequently led to adaptations in the way they participated in them.

***i) Loss of ability and loss of identity as active self.*** All participants mentioned once-valued physical activities they could no longer manage such as not being able to exercise at the gym because of inability to get on and off the equipment. Being an active person was an important part of the identity of all participants and they were proud of their past achievements. Some had been very involved in sporting activities while others described themselves as being generally active by doing chores around the house or garden. They all mentioned the enjoyment they had derived from these activities and losses were felt deeply.

*It's just the limitations of not being able to do things you used to be able to do. You move into a stage where you can't do things that you used to be able to do and I miss very much not having a license to drive a car and so I'm sort of housebound except for my wife, my wife drives me places but it's hard on her too so it's a hard time.*

The loss of important and meaningful activities, such as driving a car, affected the way people viewed themselves impacting on their sense of identity and how they were viewed both within and outside the family unit.

The importance of being physically active and the enjoyment participants derived from physical activity appeared to motivate them to continue exercise participation after their diagnosis with Parkinson's disease. Being active was integral to their identity but modifying it in some way was necessary. Examples of modifications included walking instead of running, only walking on flat ground because of poor balance, accepting assistance to get out of the swimming pool and participating in the exercise program.

*I want to keep involved in things, to do things to stimulate the brain (referring to joining the exercise program) and overcome this horrible sort of feeling that you can't do anything. I've had to give up a whole lot of things, you know.*



**ii) Focusing on not losing more.** Adapting to loss of physical ability also involved focusing on what participants could do and trying to prevent further losses. They all valued exercise as a way of doing this.

*I know without any doubt that exercise is one of the best things you can do for Parkinson's.*

Providing tension with this idea was the belief expressed by many participants that they had a fixed amount of energy and that going beyond this energy quota could be physically detrimental. This belief appeared to be related to expectations about their age rather than Parkinson's disease. Several people mentioned they could not do the prescribed exercises on days they had done a large amount of other physical activity.

*I'm just trying to hold on to what I have. I mean I am quite old. I really felt that I must not overburden the body.*

**iii) Facing the challenges of the disease and other health problems.** Most participants mentioned reduced motivation as a significant barrier to regular exercise participation. They attributed this lack of motivation to Parkinson's disease, as they had no difficulty with regular exercise prior to the onset of the disease. Several participants described the difficulty with motivation as a tiring battle.

*It is a sort of a cloudy battle in your mind with the brain sort of saying - you don't have to do this, I don't want to do it. That's the hardest part I found.*

*I knew I could do it but because it made me sort of feel tired, the battle of the wills, you know it said, "You can have a rest, you can cheat here there's nobody watching so you can have a little cheat", but I didn't really want to do that.*

Participants described successful strategies they had developed to overcome and adapt to apathy such as not accepting negative thoughts, exercising with others or joining a structured program.

*Don't listen to the surface thoughts in your mind because you'll find that you might be bombarded with negative thoughts but they're not necessarily the ones you put into action.*

Problems with fatigue interfering with exercise participation were commonly reported and participants clearly associated this sense of fatigue with Parkinson's disease.

*Yes the fatigue in that exercise, standing up and down, that was enormous, that feeling.*

Participants battled successfully to overcome many barriers to exercise but they could not overcome the effects of health conditions other than Parkinson's disease, as these were responsible for six of the eight participants not successfully completing the 6-month program.

*What happened was I ended up with a bad back and some of the exercises used to make it worse so I tried for a fair while to work my way around it but I couldn't and I'd end up limping around all the time so that's the reason I stopped, the only reason I stopped.*

### **The influence of others**

Relationships with others in the exercise group and the physiotherapist were identified as important factors in encouraging exercise participation.

**i) Relationships with a shared understanding.** Many participants mentioned the enjoyment they got from exercising with others with Parkinson's disease. Caring for each other and a shared understanding were common themes.

*It's not that you want sympathy but understanding. So when you're down there (referring to the group) I actually totally relax because we are all understanding each other.*

Most participants mentioned the importance of the relationship with the physiotherapist in motivating them. Participants valued the physiotherapist's understanding and knowledge of Parkinson's disease, leadership, guidance, feedback, the individualised tailoring of the exercise program and the opportunity to interact with the physiotherapist.

*The physio treats you as you're normal, you know, she doesn't sort of force you to do it but she's such a good leader that I wanted to do it to follow her.*

In contrast, one participant described a relationship with the physiotherapist that lacked understanding and he found this discouraging.

*There was no, "Are you having trouble with that exercise? Is it going alright?" No, there was no question it was, "Get on and let's get it over with as quickly as possible". There wasn't much communication went on between us.*

**ii) Comparison with others.** The opportunity for comparison with others was another positive aspect of exercising in a group of people with Parkinson's disease. Comparisons were made in a number of domains enabling participants to decide if their Parkinson's disease is better or worse than others. This did not appear to result in feelings of

resentment or depression and for several people seeing another person improving was motivating.

*That was an incentive for me to put more into it because I could see that one guy in particular was benefitting from it.*

For some participants, another motivating aspect of comparison with others was a sense of competition.

*Oh it's better when you're in a group because you feel more positive with everyone competing.*

Several participants described how their competitiveness had changed with the onset of Parkinson's disease from being competitive with others to being competitive with themselves.

*It's a realisation that I can't compete at the same level ... I can't hit the ball as far as I used to be able to but it hasn't denied me the competitiveness. I just make sure that I hit the dam thing straight (laughs).*

### **Making sense of the exercise experience**

Participants' comments showed that they were actively and continually evaluating their exercise experience, according to their own criteria and expectations.

**i) Identifying goals.** Participants had their own individual goals therefore each participant had different goals and expectations from the program and these were often different from the physiotherapists' goals.

*I believe that at my stage of Parkinson's progress that I have to be concerned about power and balance.*

*I have a lot of trouble motivating myself to exercise so I thought if I got onto that (the exercise program) it may well get me motivated and get me going regularly again.*

Participants' goals were dynamic in that they changed and the weighting given to them over the course of the exercise program altered. Often the goal of completing the exercise program reduced in importance when dealing with a major health problem.

*Although I came out of hospital I didn't get back to the exercises, I wasn't that well when I came out, I just wasn't motivated. I was flat out trying to get back into the normal sort of routine.*

**ii) Evaluating if expectations are met.** Participants also evaluated the effects of the exercises and the outcome of this evaluation was continually changing, for example, feeling that the exercises were improving strength one month and causing pain the next. Some participants considered broader benefits of exercise in their evaluation such as the ability to push a golf cart further or being able to ride a bike better. Some participants also evaluated the exercises in terms of their level of difficulty. Some didn't mind if the exercises appeared easy as this appeared to confirm to them that their Parkinson's disease wasn't too bad, while most expressed a definite preference for difficult exercises as they thought they would be more beneficial. There appeared to be a positive relationship between level of difficulty and interest level.

*The ones that took least time and were difficult appealed to me more than the monotony of some of the exercises.*

Some participants were motivated to continue with exercises they found boring if they felt they were beneficial and were meeting their expectations.

*That's why they are boring because they're strict and they've got to be followed. I mean I did them because I knew that I'd benefit from them but otherwise I wouldn't have done them of course.*

In contrast some participants expressed disappointment with their effort and ability to do the exercises.

*You can get disappointed if you can't do it.*

*The effort really means a lot but I just sort of glided it through somehow to get it finished ... I didn't do it to my satisfaction.*

Feedback was important for most participants and they used this information to contribute to their evaluation of their exercise experience. They valued the feedback from the physiotherapist about their performance and used this information to improve how they did the exercises and to develop more specific goals such as increasing the time they could stand on one leg or improving strength in the weaker leg.

*The physio gave me a bit of feedback like that the other day – he said this is a 5 and this is a 4 (referring to muscle strength) and that meant something to me.*

Some participants also expressed the desire for more feedback about how they were doing the exercises.

*You really need a full wall mirror or something or someone there saying "Come on there pull your shoulders back" because you tend to slack on your own.*

### **Hope for a more active future**

All participants expressed the hope that they would continue to exercise and be more active in the future. One wished to get back to swimming once his medications were

changed and another planned to keep an eye on cattle she was running on a block of land. Another who had just been discharged after a stay in hospital wished to increase her walking distance.

*We might walk for five or ten minutes until I can increase it to get right around again (a 5 km loop). That's my plan.*

### **Decision making about exercise participation**

In this study it was found that the participants' decisions to persevere with exercise were dynamic and changed according to which goal was attributed the highest priority at the time. Participants evaluated their exercise experience by weighing up the relative influences of the positive and negative factors on their exercise experience and comparing this with their goals and expectations of the program and themselves, their evolving identity and their changing priorities. If these were in alignment a decision was made to continue to exercise, even in the presence of significant barriers, but if not, a decision was made to discontinue exercise either temporarily or permanently. The interaction of these factors on exercise participation is shown schematically in Figure 3 and is illustrated by a participant's case study in Figure 4.

## **DISCUSSION**

This study aimed to explore the meaning of exercise and how factors influencing exercise participation interact in people with Parkinson's disease who have been variously successful in a minimally supervised, 6-month exercise program. The first finding of this study was that, for this group, exercise participation was a means of re-framing their identity as an 'active' person whether they dropped out of their program or not. Secondly, this study identified three important new factors that influenced exercise participation in

these people with Parkinson's disease: apathy and fatigue, belief in a finite energy quota and the importance of feedback. Thirdly, a model was developed to describe the dynamic interaction of factors that influence decision making with regard to exercise.

For the participants in this study, exercise participation was a means of reframing their identity of being 'active' which had previously been a fundamental attribute of which they were proud. Identity is our understanding of who we are and what is meaningful to us (Jenkins, 2004). Identity is not fixed but evolves with life experience, interactions with others, self-awareness and self-reflection (Jenkins, 2004). All the participants reported losses of important physical abilities and activities, associated not only with Parkinson's disease but with ageing and other health conditions, that challenged the way they viewed themselves thus impacting on their identity. The presence of a chronic disease undermines the unity between body and self and forces identity changes (Charmaz, 1995). There are two ways people with chronic illness respond to this challenge to their identity: adapting to it (reframing their identity) or struggling against it (Charmaz, 1995). Adapting involves acknowledging impairments and altering life in personally and socially acceptable ways that reunite the body and self (Charmaz, 1995). This has been described as the "salvaged self" where a past identity is retained while still acknowledging impairments (Charmaz, 1990). The participants in this study overwhelmingly reported how they adapted to losses in physical ability by modifying their activities, goals and expectations of themselves. Participation in a disease-specific exercise program, where the exercises could be modified to an appropriate level of difficulty, provided one way of adapting their exercise in a personally and socially acceptable way thereby providing a means of retaining their identity as an active person. This was not limited to participants who had successfully completed the program because all participants had plans to continue or increase their



exercise participation in the future by pursuing different activities as a way of reframing their identity. A recent qualitative study of a group of successful exercisers with Parkinson's disease described a similar process of redefining oneself due to ageing and disease progression so that the "healthy self" was not necessarily the "same old self" (Eriksson et al., 2013). Therefore, it appears that the process of reframing of identity applies to individuals with Parkinson's disease more broadly, even when exercise participation has been interrupted.

The means by which the participants reframed their identity appeared to be specifically related to the social aspect of the exercise program. The importance of social interaction as an influence on exercise participation in people with Parkinson's disease has been identified previously (O'Brien et al., 2008; Ravenek & Schneider, 2009). Aspects of social interaction and one mechanism, that of reframing identity, were found to influence exercise participation. The specific influential components of social interaction that appeared to mediate the reframing of identity in this study were the development of caring relationships and the opportunity for comparison with others. Identity is concerned with concepts of both sameness and uniqueness (Jenkins, 2004). Participants described caring and supportive relationships with others in the group that made them feel they were not alone in having the disease. Consistent with findings in the study by Eriksson et al. (2013) participants also demonstrated that they were comparing themselves with others in a number of domains with the aim of working out how their Parkinson's disease rated compared to others. Through comparison, individuals learn in what ways they are the same and what ways they are different allowing them to develop a unique identity incorporating their Parkinson's disease.

There are a number of factors, such as comorbidities and disappointment with performance, that have been previously identified as important in the decision to exercise for individuals with Parkinson's disease (Ene et al., 2011; O'Brien et al., 2008). In this study these factors were observed but three important new factors which influence exercise participation in people with Parkinson's disease were also identified: apathy and fatigue, belief in a finite energy quota and the importance of feedback.

A major finding of this study that has not been previously reported is the significant impact of the non-motor impairments of apathy and fatigue on people's decisions about whether to exercise or not. Apathy and fatigue are known non-motor impairments of Parkinson's disease (Chaudhuri et al., 2006) and there is increasing recognition of the impact of these non-motor impairments on quality of life (Barone et al., 2009; Chaudhuri et al., 2006; Gallagher et al., 2010; Khoo et al., 2013; Muller et al., 2013). Apathy has been reported to be marginally associated with reduced physical activity in the only study investigating this relationship to date (Abrantes et al., 2012). In the current study, as well as identifying apathy as a significant barrier to exercise participation, the participants described how this apathy was expressed and gave useful insights into the strategies they used to mitigate the influence of apathy as it impacted on their ability to persevere with exercise. Most participants reported that they had definite goals but felt they were fighting a constant and tiring battle with themselves to perform the steps required to achieve these goals. These participants used committing to regular exercise with others in a formal exercise program as a way of overcoming apathy. Other strategies included being aware of intrusive negative thoughts but not acting on them, rewarding themselves for perseverance and continually referring to the long-term goal. This suggests that the presence of goals and use of effective strategies can be successful in mitigating the negative effects of apathy on

decisions about whether or not to persevere with exercise. Knowledge of these strategies, if explicitly employed, might be used to assist people with Parkinson's disease for whom apathy is a significant barrier to exercise.

Fatigue was also reported as a significant barrier to exercise participation by participants in this study. Correlations between fatigue and reduced physical activity in people with Parkinson's disease have previously been identified (Abrantes et al., 2012; Elbers et al., 2009; Garber & Friedman, 2003; Rochester et al., 2006). The current study complements the findings of these quantitative studies, by providing insights about the impact of fatigue from the perspective of the individual with the disease. Many of the participants reported fatigue during exercise to be an important factor which determined whether they persevered with their exercise program. As with apathy, participants in this study had developed strategies to manage their fatigue such as doing the exercises when their medication effect was optimal, not doing specific exercises that day if they had undertaken other strenuous activities, and resting between sets of exercises. Although the effect of fatigue was still an issue for them, these strategies allowed them to persevere.

Identification of fatigue as a potential barrier to exercise participation and exploration of self-management strategies are important for clinicians implementing programs for this population.

Another factor which influenced people's decisions about exercise in this study was belief in a finite energy quota. Although the participants were engaged in physical activity and believed it was beneficial, this was tempered by another belief: that they had a finite quota of energy which, if used up, would be detrimental to their health and ability to carry out their daily activities. This energy quota idea was associated with the participants' beliefs

and expectations about ageing rather than Parkinson's disease. Beliefs are an important part of identity and can lead to certain behaviours (Jenkins, 2004). The act of matching one's physical activity level with a pre-conceived idea of how much activity one should do as an older person is a self-regulatory behaviour (Carver & Scheier, 2011). The goals of looking after their body and having enough energy for daily activities guided participants into rationing their energy expenditure so that they didn't "overdo it". For all participants, at some point in time, these goals were competing with the goal of participating in the exercise program and therefore influenced whether the exercises were done or not. This demonstrates the concept that people have many goals at any one time and they manage these by shifting between them, giving priority to different ones at different times (Carver & Scheier, 2011). This finite energy belief could conceivably influence many older people, whether they have Parkinson's disease or not. If not recognised, it has the potential to undermine all other strategies that aim to motivate these individuals to participate in exercise.

The importance participants placed on feedback from the physiotherapist regarding exercise performance and progress was another finding of this study that has not been reported previously. It is now clear that in addition to motor deficits, people with Parkinson's disease have proprioceptive deficits (Maschke et al., 2003; Zia et al., 2000) and physical performance of people with Parkinson's disease benefits from cueing which enhances motor learning (Nieuwboer et al., 2009). Individuals in the study valued the external feedback about knowledge of performance because it allowed them to know when they were doing the exercise correctly. The feedback to participants about how their balance and strength compared to normal values appeared to facilitate increased motivation by assisting the participants to formulate new goals. The experience of the

participants in this study suggests that particular attention needs to be paid to the provision of feedback and this is a particular challenge in minimally supervised exercise programs. Therefore the role of the physiotherapist to provide meaningful and tangible feedback which is related to personal goals, and can be used by the participant in their own evaluation, is crucial to their decision making with respect to continuing exercise. This might include emerging computer-based technology such as virtual reality or exergame applications (Mirelman et al., 2011; Pearce et al., 2012).

The finding that other health conditions prevented participants from completing an exercise program has been identified previously (Ene et al., 2011) and was one factor that caused six of the eight participants in this study to not complete their exercise program. Participants battled successfully with other barriers but could not overcome the impact of a reduction in health status caused by comorbidities. Commonly, the goal to complete the exercise program was seen as less of a priority in the context of deterioration in health status and recovering from the health complaint took priority. This suggests that the influence of comorbidities warrants explicit consideration, especially in the implementation of longer-term programs. Recognising that people with Parkinson's disease are likely to have other health problems that may influence their ability to exercise for some time is important. The inclusion of education about the ability to return to exercise after illness and implementing programs that allow for easy re-entry after interruption due to illness would be ways of potentially minimising this barrier.

One finding of this study, which has been briefly identified in another study (O'Brien et al., 2008), was that participants' disappointment with their exercise performance can influence exercise participation. In the context of a chronic progressive disease this is likely to be a

common occurrence. Physiotherapists often deal with people having difficulty doing an exercise by altering the exercise so it is achievable, however, it would seem that the feeling of disappointment, that is often not acknowledged, is in fact also a barrier to further participation. This suggests that physiotherapists need to listen carefully to participants' concerns about their performance to manage it effectively. This is a complex area because often a certain level of difficulty of a goal or exercise is needed to sustain engagement and certainly many of the participants in this study expressed a preference for more challenging exercises. According to goal theory, not feeling successful in making a satisfactory rate of progress towards achieving a goal can either increase effort to achieve the goal (Carver & Scheier, 2011; Mikulincer, 1988) or lead to disengagement of effort towards achieving a goal that now seems unattainable (Mikulincer, 1988). This suggests that while challenge or degree of difficulty of exercises is important it needs to be carefully monitored and managed for each individual and attention may need to be directed towards assisting the reframing of goals so that they do not become unattainable.

In this study it was clear that people's decisions about participating in the home and group exercise program were the result of a complex interaction of many influences and changed according to which goal was attributed the highest priority at the time. As has been described, the presence of a barrier to exercise did not mean that an individual will decide not to exercise and conversely the presence of motivating influences did not guarantee a decision to exercise. Rather it was the relative weighting given to these influences in reference to their priority goals at a particular time that was important in the decision-making process. Motivational interviewing, activity coaching and patient-centered care where individualised goal setting is a core element (Stretton et al., 2013; van der Eijk et al., 2011; Vong et al., 2011), may be an effective method of incorporating explicit goal

setting and dealing with the dynamic nature of goals in order to assist participants to continue with exercise.

The main limitation to this study was that the participants interviewed all placed a lot of value on exercise. 'Being active' was found to be an important part of the identity of all participants in this study therefore caution should be used in applying the findings to individuals with Parkinson's disease who do not value exercise as highly.

In conclusion this study found that, for this group, exercise participation was a means of re-framing their identity as an 'active' person as they faced losses due to Parkinson's disease and ageing. Three important new factors which influenced exercise participation in people with Parkinson's disease namely, the non-motor impairments of apathy and fatigue, belief in a finite energy quota and the importance of feedback were identified and some effective management strategies for these were suggested. In addition, using the findings of this study, a model was developed to describe the dynamic interaction of factors that influence decision making with regard to exercise in people with Parkinson's disease. Understanding the dynamic nature of these influences and their interactions and attending explicitly to these areas when developing and implementing programs could encourage sustained participation in exercise for people with Parkinson's disease. Further research into the newly identified influential issues and in more sedentary people with Parkinson's disease would be valuable and may give some direction for engaging this section of the population in exercise.

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### **Declaration of Interest**

The author declares no conflict of interest.



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**Table 1.** Participant characteristics

	<b>Mean (SD) or n (%)</b>	<b>Range</b>
Male gender	6 (75%)	
Age (y)	71 (6)	64-81
Weight (kg)	74 (16)	46-92
Height (m)	1.7 (0.1)	1.5-1.9
Hoehn & Yahr	2.5 (0.5)	2-3
Disease duration (y)	6.4 (3.7)	3-11
Fell in past year	7 (87%)	
MMSE (0-30)	29 (1)	27-30
UPDRS “on” motor score (0-108)	25 (8)	16-37
Freezing of gait questionnaire questions 3-6 (0-16)	2.6 (3.1)	0-7
Exercise on entry to study (hr/wk)	5 (3)	2-12

Hoehn and Yahr scale (Hoehn & Yahr, 1967)

UPDRS – United Parkinson’s disease rating scale (Goetz et al., 2008)

Freezing of gait questionnaire (Giladi et al., 2000)

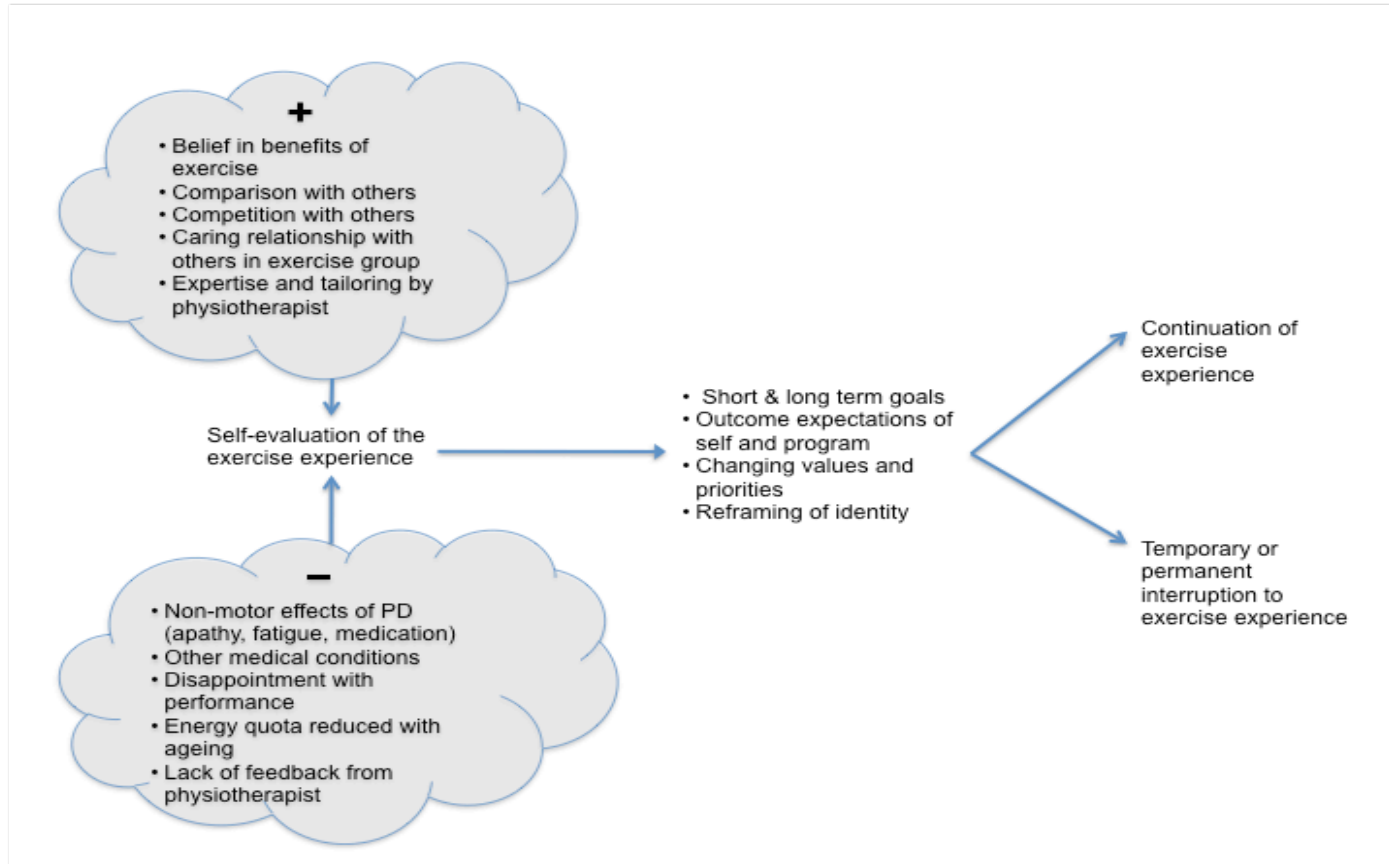
**Figure 1.** Interview questions

1. Tell me about your experience with the exercise program.
2. How did you feel when you were included in the exercise group?
3. Tell me how you felt before the exercise started and what your expectations of it were.
4. Tell me about the things that helped you to keep going with the program.
5. Was there anything about the program that made it hard?
6. Were there any major kinds of interruptions to your exercises?  
Tell me about them.
7. Tell me about how successful you feel you were in doing the exercises?
8. Before you were diagnosed with Parkinson's disease what kind of things did you do to exercise?
9. I am interested to know what your plans are now for exercising.
10. If you were to recommend this program to someone else what would you tell him or her?

**Figure 2.** Results: themes, subthemes and examples of quotes

Theme	Subthemes	Quotes
Adapting to change and loss	i) Loss of ability and loss of identity as active self	<i>With Parkinson's you do things a lot slower and you are restricted terrifically if you're not careful. I was always sort of one to go at a hundred miles an hour you know doing things, very active. Then suddenly to lose it. There is a pool here in this place that I could use but it has no ladder to get out. It has steps, very big steps and back when I was trying to use it last summer I couldn't get out without assistance. I could get in easy enough just by diving in or falling in but to get out was a difficulty on my own.</i>
	ii) Focusing on not losing more	<i>Well if you don't participate in exercise you sort of vegetate.</i>
	iii) Facing challenges of the disease, fatigue, motivation and other health problems	<i>You've got to battle with willpower all the time. If my tablet wears off I'm like as if I've been dropped at the bottom of the ocean, you know. It's as if nothing works and if the dashed tablet wore off in the middle of it (the exercises) - that was it you know. There were a couple of times when I had atrial fibrillation that I backed off - when I have AF I've got no energy</i>
The influence of others	i) Caring relationships with shared understanding	<i>The group was jovial and not only that caring for each other in a way and I think that just shaking hands and a bit of physical fellowship doesn't hurt either you know. I do have bad moments and you see down there I can hear other people saying the same thing and you know it's reassuring.</i>
	ii) Comparing oneself with others in the exercise group	<i>That was an incentive for me to put more into it because I could see that one guy in particular was benefitting from it. You keep your eye on everyone (in the group)</i>
Making sense of the exercises	i) Identifying goals	<i>I was hoping to get just a sense of well-being and maintain my health as well as I could. Part of my reasons for doing the exercise program were completely selfish - to stop me falling over, particularly with my balance.</i>
	ii) Evaluating if expectations are met	<i>I noticed myself without any prompting from them that my legs were improving and I noticed too that I fell less often. I found them a bit boring you know to just stand for 3 minutes or something or putting one foot in front of the other. The first month it was terrific. It was really good. I really did feel strong. I felt positive about it and then it sort of went po-faced when I got polymyalgia rheumatica. I don't think it (the exercise program) did much for me but then I didn't persevere with it for long enough either.</i>
Hope for a more active future	Long term goals	<i>I haven't made any decisions yet but I'm thinking about perhaps moving into swimming and going swimming perhaps twice a week. I thought well I'll just get a few cattle and just put them on there to keep the weeds down and it'll be a little interest. So I'll have that you see and the land 's about three and a half kilometers out and so I'll be going down there and wandering around and seeing how the little darlings are.</i>

**Figure 3.** Dynamic model of factors influencing decisions regarding exercise participation in people with Parkinson's disease



**Figure 4.** Case study 1: Ann

*Ann, a 65-year-old female who has had Parkinson's disease for 11 years, has exercised for fitness and enjoyment throughout her life. Ann described many heartfelt losses attributable to the effects of the disease including that she no longer attends the gym, as she is unable to get on and off the equipment independently.*

*Ann joined the exercise program with the aims of improving her balance to stop her falling and improving her hand manipulation skills. She also felt the program was something achievable and she felt there were now not many things she was able to do.*

*For Ann, the motivating factors for continued exercise participation were her belief that the exercise program could help her achieve her goals and the understanding relationship with the physiotherapist conducting the program. She was also very motivated by the idea of proving to herself that she could complete the program thus reframing her "being active" identity. Ann had significant barriers to her participation. She described a constant and very tiring battle with willpower, a problem with fatigue during the exercises, difficulties doing anything when her medication effects were wearing off, a fractured wrist and a prolonged problem with diarrhoea. Ann showed resourcefulness and determination and battled successfully to overcome these problems because she really wanted to complete the program successfully.*

*It was only when Ann had significant health problems causing hospitalisation that she ceased participating in the exercise program completely. Her priority had suddenly altered from that of achieving her goals with exercise to that of recovering her health. Ann was able to walk around her house when I interviewed her and was hoping to get back to walking 5kms in the future*



## **CASE STUDIES ILLUSTRATING MAIN THEMES AND MODEL**

One of the tasks undertaken during data analysis was to review the emerging theories with reference to individual cases to ensure the findings were a true reflection of the initial data. This was another form of the constant comparative method of grounded theory methodology. In this section three case studies are presented, including an expanded version of Figure 4 (case study included in the prepared manuscript). These case studies present the findings in a narrative form and illustrate how the themes provided meaning and how factors interact and influence the decision of whether to exercise or not on an individual basis. These cases were chosen purposefully because they are representative of both those individuals that completed the exercise program and those that did not and in addition they encompass all of the main findings from the study. Further explanation of why each case study was chosen is included at the end of each case.

### **Case study 1: Ann**

*Ann, a 65-year-old female who has had Parkinson's disease for 11 years, has exercised for fitness and enjoyment throughout her life. Ann described her view of exercise in this quote that was used at the beginning of the thesis. "Well, you look at small children rolling along the grass and doing roly-polys or hands-over catherine-wheel type things and they are laughing and giggling and challenging one another. That's what exercise is all about." Prior to being diagnosed with Parkinson's disease she attended the gym 3 times a week and played tennis. Being active was an important part of her identity; in fact her entire family, including her partner and her sons, are very involved in exercise so it is part of their collective identity as a family. Ann described many heartfelt losses attributable to the effects of the disease including the fact she no longer attends the gym, as she is unable to get on and off the equipment independently. She had to modify her exercise participation*

*and until the past few months had been walking 5 kilometers and playing tennis once a week as well as participating in the 6-month exercise program.*

*Ann joined the exercise program with the aims of improving her balance to stop her falling and improving her hand manipulation skills. She also joined because she felt the program was something achievable and she felt there were now not many things she was able to do. It was attractive to her because it was exercise, which had been such a big part of her life before.*

*For Ann the motivating factors for continued exercise participation were her belief that the exercise program could help her achieve her goals and the understanding relationship with the physiotherapist conducting the program. She was also very motivated by the idea of proving to herself and her family that she could complete the program thus reframing her “being active” identity. Ann, however, also had significant barriers to her participation. She described a constant and very tiring battle with willpower, a problem with overwhelming fatigue (non-motor impairments of Parkinson’s disease), difficulties doing anything when her medication effects were wearing off, a fractured wrist and a prolonged problem with diarrhoea. Ann was also disappointed with the overall effort she put into doing the exercises and thought that exercising in front of a mirror may have helped her do the exercises better. She showed resourcefulness and determination and battled successfully for many months to overcome these problems. She played mind games and gave herself brownie points for doing the exercises when her brain was telling her to not exercise, rested in between sets of exercise to overcome fatigue, attempted the exercises again later if she couldn’t complete them due to medication issues, exercised with a cast on her wrist and even when interrupted by bouts of diarrhoea.*

*It was only when Ann had significant health problems causing hospitalisation that she ceased participating in the exercise program completely. Her goals had changed in priority and the goal of recovering her health became more important than her goal of completing the exercises. Ann had plans to return to more exercise in the future even though she was limited to walking around the house when I interviewed her. She was hoping to get back to walking 5 kilometers once a week and was also hoping she might return to playing tennis.*

Ann's story demonstrates the significant impact of Parkinson's disease related influences on exercise participation and how an individual can battle to successfully overcome these if the goal of exercise is given high priority. Completing the exercise program was important to Ann as it helped her to adjust to losses associated with the disease and to reframe her identity as an active person. Her goal of completing the program only lowered in priority in response to a major illness requiring weeks of hospitalisation. Ann's initial goals are interesting because the goal of improving hand manipulation skills would not be obvious to the physiotherapist conducting the program unless Ann was questioned specifically about her goals. The high value she places on exercise is evident by her determination to return to exercise in the future.

### **Case study 2: Lon**

*Lon, a 70-year-old man who has been diagnosed with Parkinson's disease for 4 years, openly stated that exercise and physical activity is and has always been a very important part of his life. Lon has been involved in many sports in the past at a competitive level (canoeing, veterans tennis, athletics, surfing swimming, canoeing) and currently plays golf, rides a bike regularly, uses weights and an exercise bike at home as well as*

*frequently engaging in energetic chores around the home. He had just finished painting the outside of his house when I interviewed him. Being active was and is an important part of Lon's identity.*

*Lon didn't describe many losses associated with Parkinson's disease but he did say he was no longer as competitive as he had been. He said he managed this by making adaptations such as being competitive with himself rather than others and altering his goals. An example he gave was that he felt he had more control over his putting in golf than his long distance shots so he aimed to focus on improving his putting game.*

*Lon joined the exercise program because he wanted to improve his power and balance as well as helping research into Parkinson's disease. He had identified that his balance had deteriorated and he had fallen off his bike because of this. As "being active" was a very important part of Lon's identity he felt that participating in a disease-specific exercise program was a way of specifically addressing the disease-related issues (power and reduced balance) that were likely to impact on his ability to be active.*

*For Lon the motivating factors that assisted him to continue to exercise were a commitment to the program, the advice of his specialist, the positive interaction with the physiotherapist, challenging exercises, feedback and the benefits he observed from the exercises. Lon liked the structure of the program and said he wouldn't have done as much if he hadn't committed to it. The fact that his neurologist encouraged his exercise participation made Lon feel he was helping to manage the disease by participating. Lon also really valued his monthly interaction with the physiotherapist for her expertise and her ability to tailor the program for him so that the exercises were difficult but achievable. Lon also appreciated the feedback he received during his final assessment that informed him that his left leg was weaker than the right and he was also not able to stand on that*

*leg for 30 seconds (he could on the right leg). He valued difficult exercises as he felt they were beneficial. Lon evaluated the benefits of the exercises in a very broad fashion. He felt the exercises increased his confidence and ability to ride his bike and he was now able to push his golf cart around 18 holes whereas before he used a golf cart for 9 holes. He also felt he was able to hit the golf ball further.*

*Lon also had barriers to his continued exercise participation. He had bouts of Atrial Fibrillation, an abnormal heart rhythm, that made him feel very tired and he managed this by resting until his heart spontaneously returned to normal rhythm, usually a matter of days. As Lon was very busy with general physical activity having enough time and energy was a problem at times. He talked about having a certain amount of energy that he needed to ration. A further barrier was that Lon found some of the exercises boring and felt they were not beneficial. Another barrier was the dynamics of his exercise group. Lon compared himself to others in the exercise group and felt he was putting more effort into the exercises than the others and consequently felt alone in the group and felt he didn't get the encouragement from other participants that he hoped he would.*

*Although Lon had barriers to exercise participation his constant evaluation of these with reference to his goals motivated him to act to overcome them so that he successfully completed the 6-month program. He demonstrated resourcefulness and perseverance in overcoming these problems. He managed his lack of time and energy by doing the exercises at night and only on days that he hadn't done lots of other physical activity. He managed the boring and non-beneficial exercises by making them harder and doing less of them. He managed the lack of encouragement from the group by focusing on the positive interaction with the physiotherapist and made a point of encouraging others in the group.*

*Not only did Lon successfully complete the program he continued with doing the exercises after it had officially ended. The feedback he received from the final assessment encouraged him to continue the exercises after the program had finished with the specific aims of improving the strength of his left leg and being able to stand on his leg for 30 seconds.*

Lon's story describes how an individual can successfully continue being active as they are faced with problems due to Parkinson's disease and ageing. It demonstrates the dynamic nature of decisions made whether to exercise or not and the constant weighing up of influences to assist in the decision-making process. Lon was adept at overcoming negative influences to keep exercising and this was most probably due to skills he had developed over his extensive sporting history. Lon's story also demonstrates the dynamic nature of goals. Although the goal to complete the program generally remained high for Lon throughout the six months of the program, he did have periods where it reduced in priority (when he was too tired, too busy with other things or had atrial fibrillation), so he did not exercise on those days. This story also highlights the importance Lon placed on feedback and how he evaluated the benefits of the exercise program much more broadly than the more specific outcome measures used by physiotherapists.

### **Case study 3: Brian**

*Brian is a 70 yr old male who was diagnosed with Parkinson's disease 3 years ago. Brian has always exercised and in the past including golf, tennis, swimming and walking. He believes exercise is beneficial physically but for him this was a secondary motivating factor to the enjoyment he got from being physically active and the social aspect of*

*exercising with others. He said he did not exercise in any regimented way and liked variety so he would often change the type of physical activity he participated in. Brian described many losses due to the disease and ageing. He tried to minimise these losses by saying he realised he was better off than some people but they appeared to be very significant for him. In fact the overall impression Brian gave was that of a man grieving for the loss of his past life. He felt deeply the loss of his ability to drive and the resulting reduction in independence. He also mentioned he needed assistance to get out of the swimming pool and found last summer that he couldn't swim when he had been able to swim all his life. Brian wanted to keep exercising once he had Parkinson's disease and had been going to a hospital gym program twice a week before he started the exercise program. Even though he wanted to continue to exercise he said he didn't enjoy it as much as he had done before the onset of the disease.*

*Brian joined the exercise program to help with research, to help him become involved in regular exercise and he also thought it might help him to stop freezing and falling which were big problems for him at the time. Brian started out well, exercising three times a week and attending two group sessions. He felt he was successful in doing the exercises and had no difficulty finding the time to do them. He hadn't noticed any benefit of the exercises but felt it was too early to expect improvement. He didn't enjoy doing the exercises but said he had a sense of satisfaction from completing them. He enjoyed the shared purpose of the groups and found the commitment and the leadership of the physiotherapist inspiring.*

*A 6-week stay in hospital for a medication review interrupted Brian's participation in the exercise program. By the time he came out of hospital he had stopped falling but was sleeping a lot, didn't feel well and wasn't motivated to continue the program. His priority at that time was to get well and exercise participation had reduced in importance. When*

*he felt well enough to recommence the program he felt he had “mucked it up” by having such a big lapse so he didn’t continue. He stated that currently he had a general lack of enthusiasm as well as relationship problems with his wife and these issues appeared to pre-occupy him and trouble him greatly. Despite this he expressed plans for continuing to exercise in the future. He was not eligible to rejoin the hospital gym program so was thinking of other possible ways of exercising. He identified barriers to some to some of these plans such as cost but he thought he might pursue others such as returning to swimming. It appeared that even though Brian expressed the wish to continue to exercise his general lack of enthusiasm, his relationship problems, lack of a suitable exercise program and cost would be significant enough barriers to make exercise a lower priority goal at this time.*

Brian’s story illustrates the grief associated with losses due Parkinson’s disease, especially those such as driving, associated with independence. His story also illustrates the dynamic nature of goals and the difficulty of making exercise a high priority goal when faced with significant issues such a relationship problems with a partner and low mood. Ann and Lon demonstrated they had the skills to overcome their particular barriers to exercise but Brian, faced with different barriers, did not appear to have the necessary skills to overcome these. It seemed Brian would need professional and social support to help him feel emotionally well enough to make exercise a high priority.



## **CHAPTER 4: DISCUSSION**

### **SUMMARY OF MAIN FINDINGS**

#### **REFRAMING IDENTITY**

#### **FACTORS INFLUENCING DECISION MAKING WITH REGARD TO EXERCISE PARTICIPATION AND CLINICAL IMPLICATIONS**

**Health condition**                      *Health conditions other than Parkinson's disease*

*Parkinson's disease – non-motor impairments*

**Personal factors**                      *Belief in the benefits of exercise*

*Belief in a finite energy quota*

*Disappointment with exercise performance*

**Environmental factors**              *Competition*

*Feedback*

*Expertise and tailoring by the physiotherapist*

**Decision-making process**          *Goals*

*Hope for a more active future*

*Evaluation of the exercise experience*

#### **SUMMARY OF CLINICAL IMPLICATIONS**

#### **LIMITATIONS OF THE STUDY**

#### **DIRECTIONS FOR FURTHER RESEARCH**

#### **CONCLUSION**

#### **REFERENCES**

## **SUMMARY OF MAIN FINDINGS**

This study aimed to explore the meaning of exercise for people with Parkinson's disease who have been variously successful in a minimally supervised, 6-month exercise program and it was found that, for these people, exercise had meaning beyond improving physical ability. Exercise had meaning associated with reframing identity as people are faced with losses due to the disease. This study also aimed to explore how issues influence decisions made about exercise participation by these people with Parkinson's disease. As well as developing a model to explain the dynamic interaction of factors influencing decisions about exercise, three previously unreported factors have been identified. The non-motor impairments of apathy and fatigue, belief in a finite energy quota and the importance of feedback were found to have a significant impact on exercise participation. In this chapter, I will interpret the findings in the context of existing literature, discuss clinical implications arising from this work, address limitations of the study and make recommendations for future research.

## **REFRAMING IDENTITY**

For the participants for whom "being active" was an important part of their identity, it was found that participation in a disease-specific exercise program had meaning beyond improving physical ability. It provided these participants with the opportunity to reframe their identity as an active person as they are faced with losses due to ageing, Parkinson's disease and other health conditions. Identity is our understanding of who we are and what is meaningful to us (Jenkins, 2004). Identity is not fixed but evolves with life experience, interactions with others, self-awareness and self-reflection (Jenkins, 2004). All the participants reported losses of important physical abilities and activities associated not only with Parkinson's disease but with ageing and other health conditions that challenged

the way they viewed themselves thus impacting on their identity. The collective identity of ageing is recognised by everyone and provides its own challenges to individual identity (Walker et al., 2011) but the participants in this study were also challenged by the presence of a chronic degenerative disease. Chronic illness intrudes on daily life and undermines self and identity by shaking previously held assumptions about a smooth functioning body (Charmaz, 1995). The continual losses associated with Parkinson's disease have been described by carers as "small deaths" (Roland et al., 2010) giving an indication of the significance of these losses. There are two main ways people with chronic illness respond to this challenge to their identity: adapting to it (reframing their identity) or struggling against it (Charmaz, 1995). Adapting means acknowledging impairments and altering life in personally and socially acceptable ways that reunite the body and self (Charmaz, 1995). This has been described as the "salvaged self" where a past identity is retained while still acknowledging impairments (Charmaz, 1990). The participants in this study overwhelmingly reported how they adapted to losses in physical ability by modifying their activities, goals and expectations of themselves. Participation in a disease-specific exercise program where the exercises could be modified to an appropriate level of difficulty provided one way of adapting their exercise in a personally and socially acceptable way providing them with a means of retaining their identity as an active person. This was not limited to participants who completed the program because all participants had plans to continue or increase their exercise participation in the future by pursuing different activities as a way of reframing their identity.

Using exercise participation as a means of reframing identity is consistent with concepts in both the ageing and Parkinson's disease literature. Successful ageing is characterised by participating in valued activities and compensating when this is no longer possible by

setting new goals (Baltes & Baltes, 1993; Mallers et al., 2013). The participants in the current study demonstrated this by choosing to participate in exercise as a valued activity but altering their goals with respect to exercise as their physical ability changed. The findings of a recently published study of people with Parkinson's disease (Eriksson et al., 2013) identified, "keep moving to retain the healthy self", through exercise participation as a metaphor for maintaining health and participation in life. Eriksson described a process of redefining oneself due to ageing and disease progression so that the "healthy self" was not necessarily the "same old self" (Eriksson et al., 2013) which echoes the ideas of adapting and reframing identity identified in this study.

Participation in a disease-specific exercise program was found to enable reframing of identity as individuals are faced with losses due to the disease but this was also enabled by the social interaction that occurred in the group exercise sessions. The importance of social interaction as an influence on exercise participation in people with Parkinson's disease has been identified previously (O'Brien et al., 2008; Ravenek & Schneider, 2009) but this study provides new information on particular influential aspects of social interaction and one mechanism through which they influence exercise participation. Previous studies have focused on social support provided by others external to the exercise group such as family, work colleagues and health professionals but have not investigated the social interaction occurring between participants of the exercise groups (Ravenek & Schneider, 2009) or have identified it as an influential factor in the exercise groups but have not explored it in detail (O'Brien et al., 2008). This current study identified two specific components of social interaction that occurred between participants in the exercise group; the development of caring relationships and the opportunity for comparison with others and

found that they influenced exercise participation by mediating the reframing of identity and adjustment to having a chronic disease.

The reframing of identity was facilitated by the development of caring relationships between participants in the exercise group that fostered a sense of belonging. All human identities are social identities to some extent, relying on a dynamic process of interaction with others individually or collectively (Jenkins, 2004). Interwoven with this is the need to belong, thought to be a fundamental motivation that drives individuals to form positive relationships (Baumeister & Leary, 1995). Conditions required for the development of positive personal relationships are frequent personal interaction within a framework of concern for each other's welfare (Baumeister & Leary, 1995). Both these conditions were present in the exercise program investigated in this study. The monthly group sessions provided the opportunity for regular personal interaction and the participants described relationships involving caring for and helping one another within the group. As the participants were recruited through local support groups these caring relationships were not solely developed in the exercise group, as many participants already knew one another and had other opportunities for interaction outside the exercise group. Groups of people with the same disease offer support for each other through caring relationships between those who share the disease and they can learn from each other how to manage problems caused by the disease (Goffman, 1963). These relationships between individuals with the same disease would appear to foster a sense of belonging in the group and could potentially assist with reframing identity that includes Parkinson's disease.

There is, however, more to identity than a sense of belonging because the construction of identity involves not only the concept of sameness but also that of uniqueness and this is achieved by comparison with others (Jenkins, 2004). Participants described caring and understanding relationships with others in the group but also demonstrated that they were comparing themselves with others in a number of domains with the aim of working out how their Parkinson's disease rated in reference to others. This finding is consistent with the findings of the Eriksson study investigating the exercise experience of people with Parkinson's disease where the ability to move, presence of dyskinesia, stage of disease and age were mentioned as areas of comparison among exercise group participants (Eriksson et al., 2013). Different types of social comparison take place in support groups and these can be negative or positive. Comparing oneself with someone worse than yourself (downwards comparison) may be perceived positively, "I am doing better" or negatively, "that is how I will end up" (Dibb & Yardley, 2006a). The participants in this study reported only positive social comparison and this may be related to the homogeneity of the exercise group with respect to disease severity. This process of comparison could conceivably be a way of reframing one's identity to include Parkinson's disease. Through comparison individuals learn in what ways they are the same and what ways they are different allowing them to develop a unique identity incorporating their Parkinson's disease.

As well as enabling the reframing of identity, supportive relationships and positive social comparison with others with the same disease have been shown to assist adjustment to having a chronic disease (Dibb & Yardley, 2006b). This positive adjustment as a consequence of social comparison may be a result of an increase in self-efficacy which is mediated partly by the vicarious experience of modeling or learning through observation of other people (Bandura, 1998). The opportunity for such modeling occurs in disease-

specific groups and Bandura postulates that self-efficacy beliefs are correlated with assumed similarity (Bandura, 1998). Again the homogenous nature of the exercise group with regards to disease severity in the current study would support this.

There are limitations to the generalizability of these findings as it is likely that these views are representative of people with mild to moderate Parkinson's disease for whom exercise is important and who find exercising with others with Parkinson's disease desirable. They may not be applicable to people for whom exercise is not highly valued, those who may not choose to exercise with others with Parkinson's disease and for people with more severe disease. It is also important to note that the social interaction between participants in this study was not limited to the exercise group and that this could be an important factor in the development of caring relationships between participants. It may be that in order for caring relationships to develop opportunities for meaningful interaction need to be provided outside or alongside the exercise session.

## **FACTORS INFLUENCING DECISION MAKING WITH REGARD TO EXERCISE PARTICIPATION AND CLINICAL IMPLICATIONS**

One of the aims of this study was to explore the factors influencing exercise participation for this group of people with Parkinson's disease and to consider the interaction between these factors and how this impacts on decisions regarding exercise participation. In this section I will examine influential factors, including those newly identified, in reference to the literature, and consider the interaction of these factors in the decision-making process with regard to exercise participation.

In line with the International classification of functioning, disability and health (ICF) and the Physical activity model for people with the disability (PAD) models, the factors found to influence exercise participation will be discussed under the headings of health condition, personal factors and environmental factors.

## **Health condition**

### *Health conditions other than Parkinson's disease*

Health conditions other than Parkinson's disease were the main factor responsible for six of the eight participants interviewed in this study not completing the exercise program and this finding is consistent with one previous qualitative study of people with Parkinson's disease (Ene et al., 2011). In addition, general health status is reported to be a barrier to exercise in older adults (Schutzer & Graves, 2004). With advancing age, many health conditions are increasingly prevalent with almost half of older Australians, aged 65–74yrs, living in the community reporting five or more long-term health conditions (Australian Institute of Health and Welfare, 2012). Furthermore, two in three hospital admissions for people with Parkinson's disease are related to health conditions other than Parkinson's disease (Temlett & Thompson, 2006). Despite the high prevalence of other health conditions, there is recent evidence showing no difference in the number of co-morbidities suffered by people with Parkinson's disease who exercise regularly, versus those who do not (Ellis et al, 2011). However, non-exercisers with Parkinson's disease are almost twice as likely as exercisers to blame lack of activity on poor health (Ellis, Boudreau, et al., 2013). This suggests that both the type and number of other health conditions suffered by the person with Parkinson's disease are likely to impact on exercise participation. When health conditions were minor and the goal of completing the program remained a high priority some participants in this study modified their exercise participation and were



successful in continuing to exercise. It was generally when the health problems were major (often causing hospitalisation) that the goal of continuing to exercise reduced in significance compared to that of restoring their health and as a result the participants ceased exercising. This illustrates that goals change in response to life events and the complex interaction between goals and health status.

Taken together, these findings confirm that people with Parkinson's disease suffer from the consequences of multiple other health conditions and these conditions need to be taken into consideration when planning for and maintaining exercise participation. Recognising that people with Parkinson's disease are likely to have other health problems that may cause them to cease exercising for some time, education about the importance of returning to exercising after illness, self-management strategies that empower individuals to problem solve and implementing programs that allow for easy re-entry after interruption due to illness would be ways of minimising this barrier.

#### *Parkinson's disease – non-motor impairments*

A major finding of this study that has not been previously reported is the significant impact of the non-motor impairments of Parkinson's disease on exercise participation. Although there is increasing recognition of the non-motor impairments of Parkinson's disease, their impact on quality of life and the necessity of managing these impairments (Barone et al., 2009; Chaudhuri et al., 2006; Gallagher et al., 2010; Khoo et al., 2013; Muller et al., 2013) there has been limited investigation into their impact on physical activity (Abrantes et al., 2012; Elbers et al., 2009; Garber & Friedman, 2003; Rochester et

al., 2006). The two main non-motor impairments identified as barriers to exercise participation by the participants in this study were lack of motivation (apathy) and fatigue.

As well as identifying apathy as a significant barrier to exercise participation the participants in this study described how this apathy was expressed and gave useful insights into the strategies they used to mitigate the influence of apathy as it impacted on their ability to persevere with their home and group exercise program. The participants reported that they had definite goals but they felt they were fighting a battle with themselves to perform the steps required to achieve these goals. Many participants had developed successful strategies for overcoming apathy that included committing to regular exercise with others in a formal exercise program, being aware of intrusive negative thoughts but not acting on them, rewarding oneself for perseverance and continually referring to the long term goal when apathy occurs. This suggests that the presence of goals and use of effective strategies can be successful in mitigating the negative effects of apathy on decisions about whether or not to persevere with exercise. Knowledge of these strategies, if explicitly employed, might be used to assist people with Parkinson's disease for whom apathy is a significant barrier to exercise.

Fatigue was also reported as a significant barrier to exercise participation by some participants in this study. A weak correlation between fatigue and reduced physical activity in people with Parkinson's disease has previously been identified (Abrantes et al., 2012; Elbers et al., 2013; Elbers et al., 2009; Garber & Friedman, 2003) however, this finding has not been interpreted using qualitative methods. The participants in this study had developed strategies to overcome fatigue such as doing the exercises when their medication effect was optimal, not doing specific exercises that day if they had been

exercised during other activities and resting between sets of exercises. Although the effect of fatigue was still an issue for them, these strategies allowed them to persevere.

Acknowledgement of fatigue as a barrier to continued exercise participation and strategies for teaching self-management appear important for clinicians implementing programs for this population.

It is also conceivable that the fatigue of Parkinson's disease, described as a sense of total body inertia (Krupp & Pollina, 1996), could prevent the uptake of exercise programs in the first instance and may explain the tendency toward sedentary behaviour observed in people with Parkinson's disease (van Nimwegen et al., 2011). In the Parkfit study (van Nimwegen et al., 2013) that aimed to increase physical activity in sedentary people with Parkinson's disease, people who were most sedentary and therefore those who could possibly benefit the most, declined to participate. In the current study only people already physically active participated. This suggests that existing exercise programs might not be meeting the needs of more sedentary people with Parkinson's disease. Exercise may have a role in the management of fatigue as there is evidence that strengthening exercises increase endurance in people with Parkinson's disease (Dibble et al., 2006) and exercise may reduce fatigue in people with multiple sclerosis, another neurological disease where fatigue is an impairment (Latimer-Cheung et al., 2013). Education about the possible benefits of exercise in reducing fatigue could minimise fatigue as a barrier to initiating an exercise program. In addition, education about fatigue, management strategies such as energy conservation and attention to program design to allow for a very graduated increase in exercise intensity may begin address this problem.

## **Personal factors**

The personal factors identified as influencing exercise participation by the participants were, belief in the benefits of exercise, the belief in a finite energy quota and disappointment with exercise performance. These factors interacted with others to influence decisions made about exercise participation.

### *Belief in the benefits of exercise*

Although it was found that exercise had meaning beyond improving physical ability for the participants it did also have meaning associated with physical ability expressed in the concept of “holding onto what I have”. Participants wanted to avoid further loss associated with the disease and believed exercise was a way of achieving this. In effect, participants viewed exercise participation as a way of exerting some control over the disease. These findings are consistent with other studies of exercise in people with Parkinson’s disease and are thought to be strong motivating factors with regard to continued exercise participation (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009).

The participants’ belief that exercise was a way of exerting some control over the disease was based on specific knowledge of the benefits of exercise for Parkinson’s disease as well as their previous exercise experience. Knowledge of health risks and benefits associated with certain behaviours are recognised as creating the pre-condition for behaviour change (Bandura, 2004), but it is only part of the equation. Self-efficacy also plays a crucial role in both initiating and sustaining health behaviour change (Bandura, 2004). Previous exercise behaviour is theoretically the strongest source of self-efficacy with regard to

exercise (McAuley et al., 2003) and as mentioned previously the majority of the participants in this study had a strong history of exercise participation throughout their lives. It could be maintained that these participants had a high degree of self-efficacy for exercise, although this was not measured. Education about the benefits of exercise in general, for Parkinson's disease specifically, and drawing on previous experiences of exercise appears to be important in creating a belief in the benefit of exercise which in turn appears to be a facilitator of exercise participation.

#### *Belief in a finite energy quota*

Although the participants in this study were engaged in physical activity and believed it was beneficial, this was tempered by another belief that they had a finite quota of energy and that using more than this would be detrimental to their health and ability to carry out their daily activities. This energy quota idea was clearly associated with beliefs and expectations about ageing rather than Parkinson's disease. It should be noted however, that the reduced energy reported by participants may be also related to the unrecognised Parkinson's specific fatigue. Beliefs are an important part of identity and can lead to certain behaviours. There are many beliefs associated with ageing and the one that older people should avoid vigorous exercise in order to not damage themselves has been expressed over time from Cicero to medical practitioners of the mid 19<sup>th</sup> century (Gilleard, 2013). Although this is not quite the same as the belief expressed by the participants in this study it is similar in that it seeks to preserve an older body by not using it too strenuously. The act of matching one's physical activity level with a pre-conceived idea of how much activity one should do as an older person is a self-regulatory behaviour. Self-regulatory behaviour is a process incorporating feedback control and consists of a person making self-corrective adjustments as needed to achieve a specific goal (Carver & Scheier, 2011).

The goals of looking after their body and having enough energy for daily activities guided participants into rationing their energy expenditure so that they didn't "overdo it". For all participants, at some point in time, these goals were competing with the goal of participating in the exercise program and therefore influenced whether the exercises were done or not. This demonstrates that people have many goals at any one time and they manage these by shifting between them, giving priority to different ones at different times (Carver & Scheier, 2011).

Beliefs such as this could explain findings from the Parkfit study that investigated the effect of behavioural interventions on increasing physical activity in sedentary people with Parkinson's disease (van Nimwegen et al., 2013). After intervention, the Parkfit results showed no increase in self-reported overall physical activity using the LASA physical activity questionnaire (LAPAQ) but an increase of 1.5 hours a week measured by a 7-day activity diary. The LAPAQ includes all levels of physical activity whereas the 7-day diary includes only more strenuous activities (Stel et al., 2004). These results may indicate that participants increased their levels of strenuous activity but reduced time spent in other less strenuous activities so that they did not change their overall level of activity. This behaviour could reflect belief in the energy quota concept leading individuals to substitute usual physical activity with prescribed physical activity.

It would seem helpful for people implementing exercise programs for people with Parkinson's disease to be aware that older people with the disease hold beliefs about ageing, including the one described here. This finite energy belief could conceivably influence many older people whether they have Parkinson's disease or not. If not

recognised, it has the potential to undermine all other strategies that aim to motivate these individuals to participate in exercise. Planning for a gradual increase in physical activity, monitoring its effect and providing education about training effects may be ways of working effectively with people that hold this energy quota belief.

### *Disappointment with exercise performance*

Disappointment with performance of the exercises was another identified barrier to exercise participation by a number of participants and this has also been mentioned briefly in one other study (O'Brien et al., 2008). In the context of a chronic progressive disease this is likely to be a common occurrence. Physiotherapists often deal with people having difficulty doing an exercise by altering the exercise so it is achievable, however, it would seem that the feeling of disappointment, that is often not acknowledged, is also a barrier to further participation. This may be usefully considered in terms of the importance of challenge and goal attainment theory. A level of challenge in motor learning tasks has been shown to improve performance and it is hypothesised that this may be due to increased attention to the task (Vine et al., 2013). Certainly many participants in this study voiced a preference for more challenging exercises and this is consistent with the findings of Ene (Ene et al., 2011). In contrast, some participants were so disappointed with their performance they did not continue in the program. According to goal theory, not feeling successful in challenging activities leading to a goal can result in a range of emotions that may lead to two different adaptive responses (Carver & Scheier, 2011). The first can give rise to frustration and anger and this may cause increased effort to overcome obstacles and enhance progress (Carver & Scheier, 2011). The second response may give rise to emotions of sadness, despondency, grief and hopelessness (Finley-Jones & Brown, 1981) and this may cause the person to disengage from further effort toward a goal that now

seems unattainable (Mikulincer, 1988). This suggests that physiotherapists need to really listen to participants' concerns about their performance to manage it effectively. It appears that challenge or degree of difficulty of exercises needs to be carefully monitored and managed for each individual and attention may need to be directed towards assisting the reframing of goals so that they do not become unattainable. Motivational interviewing, activity coaching and patient-centered care where the participant and the provider agree upon goals and outcomes in a dynamic way may be suitable models to address this issue (Stretton et al., 2013; van der Eijk et al., 2011)

### **Environmental factors**

The environmental factors that participants identified as influencing exercise participation in the program are caring relationships with a shared understanding, comparison with others, competition, the importance of feedback and the expertise and tailoring by the physiotherapist. Caring relationships and comparison with others and their impact on reframing identity have been addressed earlier in this chapter so this section will focus on the remaining factors, their interaction with other influences and how this impacts on decisions regarding exercise participation.

#### *Competition*

Several participants mentioned competition as a motivating factor when participating in the monthly exercise group and this has been reported but not explored in one other study on exercise in Parkinson's disease (O'Brien et al., 2008). Interestingly, although there was some competitiveness regarding how well exercises were performed, participants were more competitive about the amount of effort they put into doing the exercises.



Competitiveness, the desire to do better when compared to others, is a type of motivational orientation and is known to have an effect on motor performance (Mayr et al., 2012). It is present to differing degrees among individuals. More males tend to have a preference for competitive situations than females and there is some evidence that competitiveness starts to decline after 50 yrs of age in both females and males (Mayr et al., 2012). Sports competitiveness has been positively correlated with levels of interest, enjoyment and motivation in exercisers of all ages (Frederick-Recascino & Schuster-Smith, 2003). The presence of others during exercise tasks can increase competitive instincts by increasing drive and attention (Anderson-Hanley et al., 2011). Competition can improve motor performance (Rhea et al., 2003) although it has also been shown that there is a gender difference in this effect and that for some tasks competition is a disadvantage for women (Mayr et al., 2012).

Most of the research into competitiveness and motor performance has been carried out in elite sports people and the relevance of these studies to older non-elite exercise group participants needs to be questioned. However, one study has investigated the effect of a virtual competitor on exercise intensity in older people and found it had a significant effect (Anderson-Hanley et al., 2011). This effect was moderated by competitiveness with more competitive participants increasing their exercise intensity more. Because competition occurs in social settings other studies have looked at the effect of social facilitation on exercise performance but the presence of others generally is thought to have only a small effect on enhancing motor performance and this depends on the complexity of the motor task and the number of people in the group (Bond & Titus, 1983; Oviatt, 2005). In summary, there is some evidence that for older competitively-oriented individuals, who are more likely to be male; the presence of competition may increase enjoyment,

motivation, exercise intensity and performance. However, for those less competitively-oriented there could be a performance disadvantage if they are placed in highly competitive situations. Several participants described how their competitiveness had changed in response to deterioration in their physical ability, moving from competitiveness with others to competitiveness within themselves. The encouragement of competition then requires careful consideration by implementers of exercise program for people with Parkinson's disease and should ideally be matched to an individual's level and type of competitiveness.

### *Feedback*

The importance participants placed on feedback from the physiotherapist regarding exercise performance and progress to increase motivation was another finding of this study that has not been previously reported. The feedback given by the physiotherapist while participants were exercising in the group involved both knowledge of performance and knowledge of results. The feedback appeared to influence motivation through two different mechanisms; that of assisting motor learning of the exercises and assisting participants to formulate future goals. There is evidence to support the use of feedback for enhanced motor learning in people with Parkinson's disease by increasing attention to the performance of the task (Nieuwboer et al., 2009). Also external feedback about limb position may be important for motor learning in people with Parkinson's disease as it may compensate for reduced sensory input from impaired proprioception. The feedback to some participants about how their balance and strength compared to normal values appeared to facilitate increased motivation by assisting the participants to formulate new goals of achieving those values. As mentioned previously knowledge regarding health risks and benefits creates a pre-condition for behaviour change (Bandura, 2004). Feedback,

especially given in conjunction with education about it's meaning in terms of function, can provide a powerful component of this knowledge.

The experience of the participants in our study suggests that particular attention needs to be paid to the provision of feedback during performance of the exercises and this is supported by research on motor learning and Parkinson's disease cited above. This is a particular challenge in minimally-supervised exercise programs such as the one in the current study. It appears that the role of the physiotherapist to provide meaningful and tangible feedback, which is related to personal goals and can be used by the participant in their own evaluation, is crucial to their decision making with respect to continuing exercise. In addition to feedback from the physiotherapist, emerging computer-based technology may be considered to enhance feedback. This is an expanding area with promising results that includes virtual reality or exergame applications (Mirelman et al., 2011; Pearce et al., 2012), use of activity monitors (Kaminsky et al., 2013; Danks et al., 2014) and utilising a combination of computers, sensing and communication devices to provide real time feedback for rehabilitation (Faria et al., 2013; Foo et al., 2013; Ruiz-Fernandez et al., 2014).

#### *Expertise and tailoring by the physiotherapist*

Supervision is known to be an important influence on exercise program adherence and effectiveness (Pentecost & Taket, 2011; Taylor et al., 2004). Although the exercise program in this current study involved minimal supervision from a physiotherapist in the group exercise situation, almost all participants valued this supervision and described the presence of the physiotherapist as a motivating factor. In contrast, one participant

described his disappointment at the lack of interest and feedback from the physiotherapist as a barrier to his exercise participation, further reinforcing its importance.

Participants also identified a number of influential components of supervision which were consistent with the existing evidence around the aspects of supervision valued by exercise participants with chronic health conditions and young people with cerebral palsy (Pentecost & Taket, 2011; Taylor et al., 2004). The factors valued by the participants in the current study were the physiotherapist's understanding and knowledge of Parkinson's disease, their leadership, guidance, feedback and the individualised tailoring of the exercise program. These can all be categorised in the informational and monitoring roles of supervision proposed by Pentecost (Pentecost & Taket, 2011). Beginning to identify the myriad of components involved in supervision of a disease-specific exercise program points to the complexity of this role. Taylor (Taylor et al., 2004) described the role of the physiotherapist supervising an exercise program in young people with cerebral palsy as an "exercise coach" and the explicit consideration of coaching techniques could be useful to enhance motivation in exercise programs for people with Parkinson's disease.

Deconstructing the role of supervision may also enhance the development of effective "virtual" coaches delivered via computer technology. The use of a virtual coach has been effective in increasing adherence to a daily walking program as well as increasing gait speed and endurance in people with Parkinson's disease (Ellis, Latham, et al., 2013).

The tailoring of the exercise program to the individual by the physiotherapist was valued highly in this study and this is consistent with findings from other studies involving people with Parkinson's disease (Ene et al., 2011) and other neurological disabilities (Kasser,

2009; Mudge et al., 2013). This obviously needs to be considered in conjunction with providing the appropriate level of challenge to motivate the individual and not cause undue disappointment with performance. The individualised tailoring of the program also reflects the idea of patient-centered treatment that is gaining increasing attention in the management of people with Parkinson's disease (van der Eijk et al., 2011) and this will be expanded upon later in this chapter.

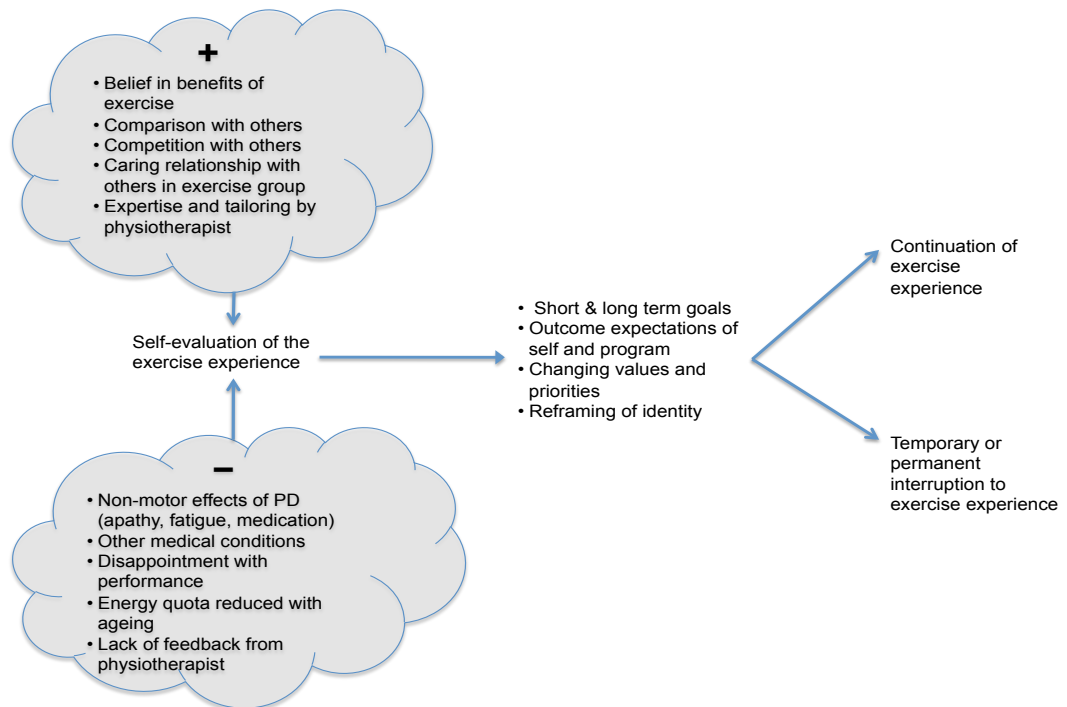
To date there is no information on the amount of supervision that could be considered a minimal requirement for a successful exercise program for people with Parkinson's disease. Many exercise programs that have been reported upon in the Parkinson's disease population have been fully supervised and have resulted in a high degree of adherence (Eriksson et al., 2013; Foster et al., 2013; Li et al., 2012; O'Brien et al., 2008; Ravenek et al., 2009). For the participants in the current study an hour of supervision once a month appeared sufficient to sustain involvement in the program. It is pertinent to remember though that the majority of participants in this study were accustomed to exercising regularly, often without supervision, therefore caution should be used in generalizing this amount of supervision to people with less extensive exercise histories. It would seem that the optimal amount of supervision will depend on the personal and disease-specific characteristics of the participants, including those factors specifically identified in this and other studies that influence exercise participation. Suitable screening of these factors prior to program entry may provide a guide to the amount required.

### **Decision-making process**

In this study it was clear that the factors influencing people's decisions to persevere with

the exercise program were dynamic and changed according to which goal was attributed the highest priority at the time. Participants evaluated their exercise experience by weighing up the relative influences of the positive and negative factors on their exercise experience and comparing this with their goals and expectations of the program and themselves, their evolving identity and their changing priorities. If these were in alignment a decision was made to continue to exercise, even in the presence of significant barriers, but if not, a decision was made to discontinue exercise either temporarily or permanently. The interaction of these factors on exercise participation is shown schematically in Figure 4.1. Although this section focuses specifically on how factors interact and influence decisions made about exercise participation this has also been addressed in the preceding section where interacting influences on each identified factor have been explored and explained. I will now explain how participants made sense of their exercise experience through self-evaluation according to personal goals and describe how the decision-making process identified in this study relates to models of health behaviour and exercise.

**Figure 4.1.** Decision-making process with regard to exercise participation



### *Goals*

For participants in this study goals were found to be a critical part of the decision-making process regarding exercise and it was clear that their goals were not static during the period of the exercise program. The importance of goals in achieving well-being through health behaviour is recognised in Bandura’s social psychosocial model which maintains that achievement goals, especially explicit and challenging goals, give activity a meaning and purpose and motivate behaviour that is likely to result in goal attainment (Bandura, 1998, 2004). If goal setting occurs in the clinical setting it tends to occur once at the commencement of an exercise program but this study highlighted the fact that goals do not remain static over the course of a longer-term program. People have many goals at any one

time and they manage these by shifting among them, giving priority to different ones at different times (Carver & Scheier, 2011). This was certainly described by many participants in this study where often the goal to complete the exercise program reduced in priority in response to an alteration in health status that made exercising impossible or ill advised. For example, one participant managed his paroxysmal atrial fibrillation by not exercising until his heart had reverted to normal rhythm (this usually took several days), while another participant realised that even after modifying the exercises they were causing back pain so he needed to stop because pain was interfering with his ability to carry out his everyday activities. It can be seen that the priority given to goals are dependent on what else is happening in a person's life.

As well as being prioritised differently, goals change over time and this was evident in this study. Commonly a new goal of regaining health emerged in response to deterioration in health. Adapting to disability from neurological disorders can involve developing new goals as well as reducing the overall number of life goals (Nair & Wade, 2003). The idea that the sadness and sense of loss associated with lack of progress towards a goal can lead to goal abandonment has been mentioned previously in this chapter (Carver & Scheier, 2011) and for some participants disappointment with their performance was a barrier to continuing to exercise. Another factor implicated in the maintenance of or abandonment of goals is the rate of progress towards goal achievement (McGrath & Adams, 1999). If the rate of progress towards achieving a goal is perceived as appropriate people are likely to maintain the goal whereas a rate of progress that is too slow may lead to goal abandonment (McGrath & Adams, 1999). Understanding the dynamic nature of goals held by people with a degenerative neurological disease, regularly reviewing goals and working towards



an acceptable rate of progress towards goals could result in more support for achieving meaningful goals, potentially leading to increased motivation.

Using patient-centered care models, where individualised goal setting is a core element, may also be an effective method of incorporating explicit goal setting and dealing with the dynamic nature of goals. A patient-centered approach to medical care is becoming increasingly recommended to improve quality of care, however evidence suggests it is not currently being implemented routinely (Lorig & Holman, 2003; van der Eijk et al., 2012). A study investigating care needs of people with Parkinson's disease identified that support for self-management, including encouragement to participate in goal setting, was lacking (van der Eijk et al., 2011). Another study investigating the low uptake of falls prevention program for older people found that although older people and physiotherapists agreed that the focus of these programs should be on self-management and support for the participants, the physiotherapists had a conflicting desire to remain in control of the treatment program (Robinson et al., 2013). Motivational interviewing and activity coaching are models incorporating patient-centered care principles that use social cognitive theory as a theoretical framework (Brodie & Inoue, 2005; Stretton et al., 2013). These have been effective in increasing physical activity in people with chronic heart failure (Brodie & Inoue, 2005) and treatment outcomes in people with low back pain (Vong et al., 2011). However, the results of the first study implementing activity coaching in sedentary people with Parkinson's disease showed no overall increase in total physical activity after the 2-year intervention (van Nimwegen et al., 2013). The Parkinson's disease-specific motor and non-motor impairments, and the limited knowledge about the interacting influences of these impairments on exercise participation may make implementing these approaches successfully in the Parkinson's population more difficult

than in people with less complex impairments. There were, however, some positive findings in van Nimwegen's study such as an increase in more strenuous activity (van Nimwegen et al., 2013). There are also promising results from studies investigating the effect of internet interventions based on behaviour change techniques on physical activity levels in sedentary people with multiple sclerosis (Dlugonski et al., 2012; Motl et al., 2011), another neurological disease with complex impairments. This suggests that these patient-centered, behavioural change approaches focusing on client goal setting may have potential benefit for people with Parkinson's disease if they are refined to consider the specific features of the disease known to impact on exercise behaviour.

#### *Hope for a more active future*

The participants in this study articulated long-term goals that indicated they hoped for a more active future. This idea of hope for a better future has been recognised in people with multiple sclerosis where exercise participation has been identified as a means of providing hope and optimism (Kasser, 2009). In the current study some of these long-term goals could be viewed as unattainable but they were important to the person. For health professionals, goals that appear unattainable and hope for the future in the context of a chronic degenerative neurological disease may appear unrealistic. Some health professionals have a paternalistic attitude towards their patients and want to protect them as they would a child (Robinson et al., 2013). This leads to actions taken by them in what they believe are in the best interests of the patient. They may attempt to point out that goals are unobtainable with the aim of saving the patient from disappointment and harm (Robinson et al., 2013). Our participants clearly articulated the hope for a more active future and this was important to them. Health professionals need to be aware of this and consider carefully how they deal with this issue. Approaches that involve regular,

collaborative goal setting may also be useful strategies for the management of long-term goals.

#### *Evaluation of the exercise experience*

Evaluation of the exercise experience was a complex process that involved participants using information from multiple sources including their own physical and emotional experience of Parkinson's disease and ageing, their social experience, their experience of the exercise program, others' experience and feedback from the physiotherapist. This information was related back to personal goals and judgments were made as to whether expectations were being met. If the program met these goals and expectations participants continued to exercise, even in the presence of significant barriers.

Self-evaluative behaviour has been identified in Bandura's psychosocial model of health behaviour (Bandura, 2004) as a category of outcome expectations. The evidence supports the importance of outcome expectations and self-efficacy for initiating health behaviour change (Resnick et al., 2002; Rothman et al., 2011) but because maintenance of the desired health behaviour is as important as initiation researchers are now also investigating the factors that influence behaviour maintenance. Self-efficacy still appears to be important in the maintenance phase (Brassington et al., 2002), however, evidence is emerging that suggests that during this phase the focus shifts away from outcome expectations to the actual experience of the behaviour (Brassington et al., 2002; Rothman et al., 2011). This means that decisions about continuing the behaviour are based on deciding if the experience of the behaviour is sufficiently desirable to continue to pursue it (Rothman et al., 2011).

Rothman has proposed four stages of behaviour change; the initial response phase, the continued response phase, the maintenance phase and the habit phase (Rothman et al., 2011). The first two stages involve initiating the new behaviour and managing the effort and challenges required to sustain it. The maintenance phase involves the continuation of a behaviour based on continual evaluation of the behaviour's value and the habit phase is when the behaviour is continued without any consideration of an alternative behaviour (Rothman et al., 2011). The participants in the current study clearly described features of the first three of these stages and their reliance on their actual experience of the exercise program to inform their decision making about continuing exercise participation supports this model. This model could also explain the value the participants placed on feedback regarding exercise performance. Positive fitness outcome realisations were related to adherence to an exercise program in a 12-month intervention for sedentary older adults (Brassington et al., 2002), suggesting that if participants are aware of improvement in performance and fitness through feedback as well as their own assessment they are more likely to adhere to the program.

The finding that the actual experience of the exercise program is an important factor influencing continued exercise participation has significant clinical implications. It is encouraging in that the experience of the program can be modified to certain extent to become desirable enough for participants to pursue. This study has identified a number of factors that influenced the experience of the exercise program such as developing caring and supportive relationships in the group, the supervision and individualised tailoring by the physiotherapist, providing feedback, attention to challenge level and competition and these can all be considered explicitly when implementing exercise programs to enhance

the desirability of the exercise experience. Assisting people to access a variety of different ways of exercising to enable people to find a program that fits with their exercise preference would also appear to be important in making the experience desirable.

The actual experience of the exercise program, as well as being used in self-evaluation, also has a relationship with self-efficacy, an established mechanism for initiation and maintenance of health behaviour in older people (Brassington et al., 2002; McAuley et al., 2003) and in people with Parkinson's disease (Ellis et al., 2011). Self-efficacy is increased via several mechanisms, three of which are mastery, vicarious modeling and social persuasion (Bandura, 1998). It is likely that these mechanisms could occur in the experience of a group exercise program. An appropriately challenging exercise program carried out with a group of similar people with feedback from the physiotherapist and encouragement from the physiotherapist and others in the group would address all three of these mediating factors and could potentially increase self-efficacy.

The positive clinical message derived from these findings is that an exercise program delivering a desirable experience for the participant through consideration of the factors mentioned above can theoretically continually increase self-efficacy, which in turn can encourage the maintenance of the exercise behaviour.

The participants in this study constantly evaluated their exercise experience with reference to their current goals and this was key in their decision of whether to exercise or not. It can be seen from the participants' experience that merely the presence of barriers to exercise does not mean individuals will decide not to exercise and conversely the presence of

motivating influences did not guarantee a decision to exercise. If the goal to exercise was a high priority the participants battled with negative influences and in many cases were able to successfully overcome them so they could continue to exercise. The fact that they were able to do this indicates that they probably had a high degree of self-efficacy and this is also supported by the fact they all had a history of exercise participation throughout their lives. This process of decision making is consistent with the concept that goals, self evaluation and self-efficacy are important in achieving health behaviours as outlined in Bandura's social cognitive model (Bandura, 2004). Although it is useful to identify factors influencing exercise participation in people with Parkinson's disease it seems essential to go beyond this to develop models explaining their interaction and how they exert their influence. This research has led to the development of a model that attempts to explain this process as it occurred for the participants involved in this study.

The decision-making process identified in this study may be useful to consider for other patient populations, as it is likely that the central idea of continual re-calibration of goals in response to experience is a factor common to many groups. It is clear, however, that the presence of a chronic degenerative disease with multifarious impairments such as Parkinson's disease adds a degree of complexity to the decision making process that may not be present in patient populations with more stable impairments such as stroke.

## **SUMMARY OF CLINICAL IMPLICATIONS**

One of the main aims of this study was to gain insights from this group of people with Parkinson's disease regarding exercise participation and from this to develop recommendations for improving the implementation of exercise programs for this

population. The clinical implications of this research have been presented throughout this chapter. In summary, it is important for clinicians to be aware that participation in a disease-specific exercise program may go beyond physical considerations and enable reframing of identity facilitated by the social interaction of the participants. The non-motor impairments of apathy and fatigue, the belief in a finite exercise quota and the importance of feedback are specific factors that need to be addressed when developing exercise programs for people with Parkinson's disease. It is also important to understand that people make decisions about whether to exercise or not based on their own evaluation of their exercise experience. Goals, which are dynamic, are crucial in this process.

For the participants of this study who were used to exercising regularly, the design of the exercise program that included individual home-exercise in addition to a once a month supervised group session appeared to be effective. As explained previously, the main reason for non-completion was related to an alteration in goals following deterioration in health status. All participants who did not complete the program had plans to return to exercise. If the program had lasted longer than 6 months, allowing for re-entry after a break, it is feasible that these participants would have continued with the program. It seems therefore that there is a place for minimally supervised exercise programs for some individuals with Parkinson's disease

An additional clinical implication from these findings is that physiotherapists implementing exercise programs for people with Parkinson's disease may need to carefully consider and review the use of measurement tools. If, as found in this study, exercise participation has meaning beyond physical improvements, utilising only outcome measures that measure physical ability may not capture the full effects of an exercise

program. In addition it would seem that measurement tools designed to measure the impact of some influential non-motor impairments could assist in identifying individuals for whom these are significant problems. This could in turn lead to the development of targeted interventions designed to assist individuals in overcoming these. Although these tools are still in the early stages of development and validation for use in people with Parkinson's disease there are some for fatigue, apathy and anhedonia that are recommended for use by the International Movement Disorders Society (IMDS). These are the Apathy Scale and the Lille Apathy Rating Scale for apathy and the Snaith-Hamilton Pleasure Scale for anhedonia (Leentjens et al., 2008). Fatigue measurement tools recommended by the IMDS are the Multi-dimensional Fatigue Inventory and the Fatigue Severity Scale (Friedman et al., 2011).

The findings from this study also raise awareness that this type of exercise program appeared to attract people with Parkinson's disease who have been already exercising regularly and therefore raises questions about the types of programs that would cater for more sedentary people with Parkinson's disease. It would seem that implementers of exercise programs should consider alternative and innovative ways to engage the sedentary portion of the Parkinson's disease community in exercise.

#### **LIMITATIONS OF THE STUDY**

The main limitation of this study is that all of the participants valued exercise highly, had an extensive exercise history and volunteered to participate in exercise research. The participants also had good knowledge about the benefits of exercise generally and for Parkinson's disease in particular. This raises questions about the applicability of these



findings to more sedentary people with Parkinson's disease and those without knowledge of the benefits of exercise or an extensive exercise history.

Other limitations of this study were that all of the participants had mild-moderate Parkinson's disease (Hoehn & Yahr stage 2-3) and were at risk of falls. Since this is a relatively homogeneous group, caution should be used in applying these findings to people with both early and more severe disease as well as to more heterogeneous groups.

### **DIRECTIONS FOR FURTHER RESEARCH**

The qualitative research to date has focused primarily on mild to moderately-affected individuals with Parkinson's disease who were undertaking, or had recently completed, a prescribed exercise program (Ene et al., 2011; Eriksson et al., 2013; O'Brien et al., 2008; Ravenek & Schneider, 2009). The model of interacting factors influencing exercise participation developed in this study needs to be tested more broadly to determine whether it explains exercise participation of people with Parkinson's disease in those individuals with more mild and more severe disease, as well as those who are sedentary and those who were not regular exercisers prior to diagnosis. In addition, it is critical to determine whether yet unidentified factors influence the exercise experience of these individuals. It may also be useful to combine other measurements, such as self-efficacy, with further qualitative research to determine if the factors influencing decision-making around exercise can be linked to participant characteristics.

Sustained participation in exercise is ideal for people with Parkinson's disease but as discussed this can be complicated by the non-motor effects of the disease. Fatigue and apathy in particular were identified as barriers to continued exercise participation for the participants of this study and further research into these as potentially powerful barriers to both initiation and continued exercise participation is warranted. The findings of this study also suggest that further research into beliefs about a finite energy quota would be worthwhile. It would be interesting to investigate if this belief is present in more sedentary people with Parkinson's disease, to attempt to quantify the quota in different groups and explore if there is a relationship with fatigue. The impact of other health conditions on exercise participation in people with Parkinson's disease is also clearly important and further research into the types of health conditions that have the most impact and the presence of these in people with more severe disease or those who are more sedentary would be informative.

Further investigation into the use of patient centered models of behaviour change such as motivational interviewing and activity coaching to encourage exercise participation would also be useful as they appear to have the potential to be effective due to their individualised, collaborative approach and their ability to respond to changes in an individual's goals and priorities. Van Nimwegen's study (van Nimwegen et al., 2013) found the use of these models had little impact on overall level of physical activity but did alter the type of activity undertaken, indicating that implementing these models in sedentary people with Parkinson's disease is complex and requires further investigation. As explained previously the idea of a finite energy quota could explain some results from the van Nimwegen study (van Nimwegen et al., 2013), suggesting that further investigation and consideration of this idea in sedentary people may be worthwhile. As

well, a further exploration of the meaning of exercise for sedentary people with Parkinson's disease may help guide the interventions needed to engage this population in regular exercise.

This study identified supervision, feedback and competition as motivating influences on exercise participation and there has been some promising research on the delivery of coaching techniques, feedback and competition through exergame technology in older people and people with neurological conditions (Anderson-Hanley et al., 2011; Snyder et al., 2012). Investigation of the use of Internet interventions based on behaviour change theory to increase physical activity in sedentary people with Multiple Sclerosis also shows potential (Dlugonski et al., 2012; Motl et al., 2011). The use of computer technology to deliver physical activity and exercise interventions as an adjunct or to replace face to face consultations in people with Parkinson's disease is another area that warrants further research.

## **CONCLUSION**

This study aimed to investigate the meaning of exercise and to understand more deeply how factors influence decision making regarding exercise participation in people with Parkinson's disease who had recently undertaken a 6-month, minimally supervised exercise program with varying degrees of adherence, with the aim of developing recommendations to improve the implementation of exercise programs. In conclusion this study found that, for this group, exercise participation was a means of re-framing their identity as an 'active' person as they faced losses due to Parkinson's disease and ageing. Three important new factors which influenced exercise participation were identified in

people with Parkinson's disease: the non-motor impairments of apathy and fatigue, belief in a finite energy quota and the importance of feedback. Some effective management strategies for these were suggested. In addition, using the findings of this study, a model was developed to describe the dynamic interaction of factors that influence decision making with regard to exercise in this group of people with Parkinson's disease.

Understanding the dynamic nature of these influences and their interactions and attending explicitly to these areas when developing and implementing programs could encourage sustained participation in exercise for people with Parkinson's disease.

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## **APPENDIX 1: RECRUITMENT, SAFETY, CONFIDENTIALITY AND FEEDBACK TO PARTICIPANTS**

### **RECRUITMENT**

On completion of post-test assessment the research assistant from the exercise for falls prevention trial<sup>1</sup>, who was not associated with this research project, provided possible participants with a participant information statement (see below). I contacted these individuals by phone one week later to provide an opportunity for them to ask any questions. At the beginning of the follow up phone call it was explained again that they were free to decide to participate or not. Participation was voluntary and participants were informed that they were able to withdraw at any time. They were reminded of this prior to the commencement of the interview. All participants gave written consent prior to the interview (see consent form below).

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<sup>1</sup> Canning, C. G., Sherrington, C., Lord, S. R., Fung, V. S., Close, J. C., Latt, M. D., . . . Murray, S. M. (2009). Exercise therapy for prevention of falls in people with Parkinson's disease: a protocol for a randomised controlled trial and economic evaluation. *BMC Neurol*, 9(4), 4.

## Participant information statement



**The University of Sydney**

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### *The University of Sydney PARTICIPANT INFORMATION STATEMENT*

#### ***Motivating factors and barriers to exercise in people who have Parkinson's disease***

You are invited to take part in a research study looking at what helped you participate in the Parkinson's disease Weight Bearing Exercise for Better Balance (PDWEBB) exercise program and which factors made it difficult for you.

#### **What is this project?**

The project aims to explore the factors associated with the uptake of falls prevention programs for people living with Parkinson's disease. The project will involve interviews with participants who were involved in the PDWEBB exercise program. The study is being conducted by Dr Colleen Canning, Associate Professor Lindy Clemson and Christine O'Brien from The University of Sydney. The study will form the basis for the degree of Master of Applied Science at the University of Sydney for Christine O'Brien.

#### **What do you need to do?**

If you agree to participate in this study, our researcher, Christine O'Brien, will interview you. The interview will take about one hour. The interview will be arranged at a mutually agreeable time and place for you. We will take notes within the interview and record the interview electronically or with an audiotape. This is so we can be sure we capture the meanings and words that you use.

#### **What are the benefits of participating?**

By participating in this project you will:

- Contribute to our understanding of the factors associated with the uptake of falls prevention programs by people who are living with Parkinson's disease.
- Provide important information about ways to improve falls prevention programs for people who are living with Parkinson's disease.

- While we intend that this research study furthers medical knowledge and may improve treatment of this condition in the future, it may not be of direct benefit to you.

### **Confidentiality**

Your name will not be attached to any of the data we collect. All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to any information collected. When the information is analyzed and written up for publication, no identifying information will be used. The results of this project will be published in medical journals and presented at conferences.

### **Your rights**

Participation in this research project is entirely voluntary. You are not obliged to participate and - if you do participate - you can withdraw at any time. You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

When you have read this information please ask any questions you may have.

### **Contact for further information**

If you would like to know more at any stage, please feel free to contact Christine O'Brien, 0418 207 990 or Dr Colleen Canning, 9351 9263. This information sheet is for you to keep.

### **What do I do now?**

Our researcher, Christine O'Brien, will contact you by phone in the next week to see if you would like to participate in the study. Please remember you are under no obligation to participate and whatever decision you make will be respected.

Thank you for taking the time to read this.

**Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au) (Email).**

# Participant consent form



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## PARTICIPANT CONSENT FORM

I, .....[PRINT NAME], give consent to my participation in the research project

### **Motivating factors and barriers to exercise in people who have Parkinsons Disease**

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved (including any inconvenience, risk, discomfort or side effect, and of their implications) have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to: –

- i) Audio-taping YES  NO   
ii) Receiving Feedback YES  NO

If you answered YES to the "Receiving Feedback Question (ii)", please provide your details i.e. mailing address, email address.

**Feedback Option**

**Address:** \_\_\_\_\_  
\_\_\_\_\_

**Email:** \_\_\_\_\_

**Signed:** .....

**Name:** .....

**Date:** .....

## **CONFIDENTIALITY**

Interviews were digitally recorded then transcribed verbatim for coding. ID numbers were used for identification purposes. Pseudonyms were utilised for direct quotes when disseminating information to ensure anonymity of participants.

## **SAFETY**

As the interview took place in the participant's home a safety protocol for home visits was developed and adhered to (see safety protocol below).

### **Safety protocol**

#### **SAFETY PROTOCOL FOR HOME INTERVIEWS**

##### **Background**

- The participants in this study have recently completed a study which included home visits carried out by a research assistant (physiotherapist) for physical assessment and exercise training.
- The student researcher (Christine O'Brien) in this study is a qualified physiotherapist and teacher with extensive experience in provision of physiotherapy services in the community.

##### **For each home visit interview the following protocol will be followed:**

- The student researcher will wear her University of Sydney name badge.
- The student researcher will carry a mobile phone with her at all times during the home visit. This will have the contact phone number of the chief investigator (Dr Colleen Canning – 0415 300 337) and two other responsible individuals programmed into it (for use in an emergency).
- Prior to each home visit the student researcher will provide the Chief Investigator (or a suitable responsible local professional) with the name, address and phone number of the home to be visited as well as the expected duration of the visit.
- On completion of each home visit, the student researcher will notify the Chief Investigator (or a suitable responsible local professional).



## **FEEDBACK**

Participants were given the opportunity to request feedback about the study when they signed the consent form. A feedback letter outlining the findings was sent to all participants who requested feedback in October 2013 (see feedback letter below).

# Participant feedback letter



Clinical &  
Rehabilitation Sciences  
Research Group  
Discipline of  
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## *The University of Sydney feedback to participants*

### *Motivating factors and barriers to exercise in people who have Parkinsons Disease*

Dear,

We would like to thank you for taking part in our research project investigating the experience of exercise for people with Parkinson's disease. You may remember you did this by being interviewed by me (Christine O'Brien) at the end of 2010.

We are now coming to the end of this project and would like to let you know some of our main findings.

#### **Exercising with Parkinson's disease**

##### ***Adapting the exercise***

We found that exercise or physical activity played an important part of people lives before they had Parkinson's disease and that people wanted to continue participating in exercise and physical activity with the disease. Continuing to exercise with Parkinson's disease often meant doing different activities or adapting activities to take into account the movement difficulties associated with the disease. Participating in a Parkinson's disease-specific exercise program was one way of keeping active with the disease.

##### ***Facing the challenges of the disease and other health problems***

Participants battled with non-movement aspects of the disease in order to keep exercising. These included problems with motivation, fatigue and medication issues. People also had to overcome problems associated with other health conditions in order to keep exercising. People demonstrated they were often very successful in overcoming these difficulties and showed great resourcefulness and resilience in this regard.

##### ***Exercising in a group***

Participants generally enjoyed exercising in a group with most people finding it a supportive and encouraging environment. Some people mentioned they enjoyed the competitive aspect of exercising with others and found this motivating.

##### ***Making sense of the exercise experience***

Participants also showed that they had definite goals with regard to exercising and that they continually evaluated how they were going with the exercises. Some people were pleased with

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how they went while others were disappointed with their efforts. Some people who were disappointed with their efforts didn't complete the program.

#### **Recommendations**

The aim of this project was to improve exercise programs for people with Parkinson's disease by using the insights gained from the participants of this study. Some of the recommendations for improving the implementation of such programs include:

- Health professionals should understand that exercising in a group of others with Parkinson's disease can have meaning for the participants beyond improving physical function and that the social support and interaction of the group is an important factor helping people manage the disease and in motivating people to continue to exercise.
- Health professionals need to be aware that individuals have their own goals and conduct their own evaluation of the exercise experience. Health professionals conducting programs should endeavor to understand participant's goals and help them achieve them. They should also provide feedback on exercise performance and outcomes to help participants work out if they have achieved their goals.
- Health professionals need to understand the significant impact of the non-movement effects of Parkinson's disease and other health conditions on the ability of people to exercise. They should be encouraged to develop strategies to help people with Parkinson's disease manage deterrents such as apathy and fatigue and design programs that allow for easy re-entry after interruption due to illness.

#### **Dissemination of findings**

The results of this study have been presented at conferences such as the Parkinson's Australia conference, The Movement Disorders Society Congress and the Australian Physiotherapy Association conference and we have recently submitted a research paper in the hope that it will be published in the Journal of Physiotherapy. I have been very careful not to include any information that could identify you personally when I have shared my results.

I would like to thank you again for your contribution to the body of knowledge about exercise and Parkinson's disease which will hopefully lead to the improved provision of exercise programs for people with Parkinson's disease.

If you have any comments or queries regarding this research please contact Christine O'Brien via email [cobr6714@uni.sydney.edu.au](mailto:cobr6714@uni.sydney.edu.au) or by mobile 0418 207 990.

Yours faithfully,

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