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The Parkinson's experience of group physical activity: Understanding social support, social comparison, physical self-perceptions, and posttraumatic growth

Tammy L. Sheehy
Purdue University

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Approved by Major Professor(s): Meghan McDonough

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THE PARKINSON'S EXPERIENCE OF GROUP PHYSICAL ACTIVITY: UNDERSTANDING SOCIAL SUPPORT, SOCIAL COMPARISON, PHYSICAL SELF-PERCEPTIONS, AND POSTTRAUMATIC GROWTH

A Thesis

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ABSTRACT

Sheehy, Tammy L. M.S., Purdue University, August 2014. The Parkinson’s Experience of Group Physical Activity: Understanding Social Support, Social Comparison, Physical Self-Perceptions, and Posttraumatic Growth. Major Professor: Meghan McDonough.

Group physical activity programs for clinical populations can provide opportunities for adaptive social interactions, improving perceptions of competence, and may facilitate posttraumatic growth (positive psychological changes resulting from traumatic life experiences). Therefore, the purpose of this study was to examine how people with Parkinson’s experience social interactions and physical challenges in a group physical activity program, and to investigate what role they think those experiences play in posttraumatic growth. The study employed interpretative phenomenological analysis methodology (Smith, Flowers & Larkin, 2009). N= 20 participants (n = 12 women; age = 56-79 years) in a boxing-based group exercise program for people with Parkinson’s were interviewed. The findings included four collective narratives characterized by (1) finding a safe space in the program; (2) perceiving improvement in symptoms through self-regulation despite loss of control; (3) anxiety relief through shared humor with others who have Parkinson’s; and (4) focusing on helping others in lower level classes. The findings of this research may have important implications for how to structure adaptive group physical activity programs for those with Parkinson’s disease.

CHAPTER 1. INTRODUCTION

1.1 Introduction

Parkinson’s disease is a progressive, neurodegenerative illness which can lead to decades of severe disability (Bramley & Eatough, 2005). Although there are gaps in the knowledge of the neuropathology of the disease, progressive death of dopaminergic neurons of the pars compacta leaves people with a deficiency of dopamine in the nervous system (Lang & Lozano, 1998). This lack of dopamine leads to motor symptoms such as tremor, bradykinesia, postural rigidity, and postural instability (Jankovic, 2008), and non-motor symptoms such as depression, constipation, pain, genitourinary problems, and sleep disorders (Chaudhuri, Healy, & Schapira, 2006). The degree and combination of symptoms experienced is variable to each individual.

Symptoms are typically treated with medication, surgery, physical therapy, or a combination of these. For non-motor symptoms, treatments are often limited to medication such as anti-depressants or therapy. Whereas for motor symptoms, there are a broader range of treatments available. Levodopa remains the most effective medication for controlling most motor symptoms. However, as Parkinson’s progresses and symptomology worsens levodopa treatment gradually results in a number of adverse secondary effects such as motor fluctuations (Soulas, Sultan, Gurruchaga, Palfi, & Fenelon, 2011) and people become increasingly immobile, homebound, and dependent on others (Brod, Mendelsohn, & Roberts, 1998). Deep brain stimulation surgery is suitable for mitigating some symptoms, and/or directly diminishing the side effects induced by Parkinsonian medications (Limousin, Krack, Pollak, Benazzouz, Ardouin, Hoffmann, Benabid, 1998). However, this surgery only helps a very small population and addresses only a subset of Parkinsonian symptoms. The progressively increasing impairment induced by Parkinson's also leads to restrictions in participation in domestic life and social activities (Giladi & Balash, 2006). Physical therapy can provide help with some of these impairments and restrictions. The main goals of physical therapy are to improve physical limitations in gait, physical capacity (i.e. strength, mobility and endurance), posture, and balance (Keus, Bloem, Verbaan, de Jonge, Hofman, van Hilten, & Munneke, 2004). However, these treatments often focus on only treating the symptom and fail to provide help for coping with the disease and enhancing psychological well-being. Given the limitations with treatments for motor and non-motor symptoms, and the lack of focus on coping and psychological well-being, there is an increasing need for understanding ways in which to both help lessen the severity of symptoms and enhance psychological well-being for those with Parkinson's disease.

Physical activity has been shown to be effective in reducing the severity of physical symptoms and have a positive effect on perceived quality of life (e.g., Combs, Dier Diehl, Staples, Conn, Davis, Lewis, & Schaneman, 2011), as well as increased self-efficacy (e.g., Cakit, Saracoglu, Genc, & Erdem, 2007) for those with Parkinson's disease. Furthermore, physical activity is a potential treatment that has few negative side effects and can be used as a treatment early in the disease, or as an adjunct to medication later on (Alberts, Linder, Penko, Lowe, & Phillips, 2011). For example, Canning, Allen, Dean, Goh, and Fung (2012) conducted a home-based treadmill training intervention with Parkinson's patients and found that those in the treadmill group showed a greater improvement than the control group in fatigue at post-test and in quality of life at six weeks follow-up testing. Additionally, Hirsch, Toole, Maitland, & Rider (2003) conducted a resistance training and balance training study with people with Parkinson's and findings showed substantial improvements in both balance and muscle strength in the combined resistance and balance group compared to the balance only group, and this effect persisted for at least four weeks. It seems that physical activity may be a useful treatment for helping to decrease the severity of symptoms and increase psychological well-being in those with Parkinson's. Additionally, Previous research has found that people with progressive neurological conditions, including Parkinson's, prefer to exercise in a group of people with the same or other disabilities, rather than alone (Elsworth, Dawes, Sackley, Soundy, Howells, Wade, Hilton-Jones, Freebody, & Izadi, 2009), therefore, physical activity in a group environment may be beneficial for those with Parkinson's.

Research with individuals in clinical populations, such as breast cancer survivors, has shown that group physical activity can provide opportunities for positive outcomes such as improved physical-self-perceptions (e.g., Hackney & Earhart, 2010; McDonough, Sabiston, & Crocker, 2008; Sunvissan & Eckman, 2001), social support (e.g., Hackney & Earhart, 2009a; McDonough, Sabiston, & Ullrich-French, 2011), and positive psychological growth such as posttraumatic growth (e.g., Hefferon, Grealy, & Mutrie, 2008; Sabiston, McDonough, & Crocker, 2007; McDonough et al., 2011). While there are a few studies examining these concepts in people with Parkinson's, there is little work examining participants' interpretations of their experiences of group physical activity and how they understand their participation to lead to such outcomes.

In breast cancer survivors, research has shown that participating in group physical activity may provide opportunities to overcome physical challenges and enhance perceptions of control (McDonough et al., 2008). However, unlike diseases such as cancer, Parkinson's leads to progressive motor impairment and a sense of loss of physical control (Ravenek & Schneider, 2009). Some studies have shown that physical activity can reduce motor symptoms (e.g., Canning, Allen, Dean, Goh, & Fung, 2012; Ridgel, Peacock, Fickes, & Kim, 2012) and this may affect people with Parkinson's expectations and motives for being physically active. For example, people with Parkinson's may have expectations that physical activity can improve aspects of the disease and slow down the progression. Furthermore, physical activity has been shown to increase self-efficacy and competence in those with Parkinson's. For example, Cakit, Saracoglu, Genc, and Erdem (2007) found that people with Parkinson's had greater efficacy to prevent falling following incremental speed-dependent treadmill training. Additionally, Heiberger, Maurer, Amtage, Mendez-Balbuena, Schulte-Monting, Hepp-Reymond, & Kristeva (2011) found that following a dance program, people with Parkinson's felt more positive about everyday competence, which included independence in activities of daily living and mobility. Hackney and Earhart (2010) also found that tango dancing increased balance confidence in those with Parkinson's. Increases in self-efficacy and competence may lead to positive changes in physical self-perceptions; however, little is known about how self-perceptions change over the course of participation in group physical activity programs among those with Parkinson's. One qualitative study found that, following a group physical activity program, participants expressed feelings of capability, a sense of endurance, and a sense of confidence in their ability to overcome their symptoms (Sunvisson & Eckman, 2001). While this study gives some insight into how people with Parkinson's view their self-perceptions following a group physical activity program, little is known about how people with Parkinson's understand and interpret their experiences with physical challenges during participation in group physical activity and how their expectations for being physically active may influence their perceptions.

Physical activity programs which are conducted in a group setting may also create opportunities for social integration, and the development of social support networks (McAuley, Blissmer, Marquez, Jerome, Kramer, & Katula, 2000). Given that social support has been shown to be an important factor for coping with Parkinson's disease (Brod, et al., 1998; MacCarthy & Brown, 1989; Marr, 1991; Pretzer-Aboff, Galik, & Resnick, 2009; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006), group physical activity may be an adaptive setting in which to receive such support. For example, people with Parkinson's disease in a group tango dancing program showed significant increases in social support and social interactions (Hackney & Earhart, 2009a).

Being in a group environment can also elicit social comparison. Research suggests that social comparison may play an important role in coping with health problems, specifically, that when one is confronted with serious health problems, they seek to relate their own situation to the situation of others in order to increase their subjective well-being (Van der Zee, Buunk, Sanderman, Botke, & van der Bergh, 2000). Though little research has examined social comparison processes in those with Parkinson's disease, those with cancer have been shown to favor dissociating from those worse off than oneself and affiliating to those better off than oneself resulting in self-enhancement (Carmack Taylor, Kulik, Badr, Smith, Basen-Engquist, Penedo, & Gritz, 2007; Van der Zee et al., 2000). For someone with Parkinson's, however, such comparisons may not be realistic given the progressive nature of the disease in which people know they will eventually worsen over time. Buunk, Collins, Taylor, VanYperen, and Dakof (1990) have suggested that the comparisons one makes and the development of a positive or negative perception is dependent upon the likelihood of reaching the target's level in the future. Therefore, for someone with cancer, seeing others who have recovered and are doing well may elicit positive feelings of connection as they believe they could also reach that level of wellness. Comparatively, someone at an earlier stage of Parkinson's may see a connection with someone at a later stage of the disease given their knowledge that their symptoms will progress in the future, and this may elicit negative feelings about the self.

Improvements in physical self-perceptions and social support in group physical activity for clinical populations may also facilitate posttraumatic growth (Hefferon et al., 2008; McDonough et al., 2011; Sabiston et al., 2007). Posttraumatic growth is positive psychological change that can occur as a person psychologically rebuilds in the wake of a traumatic experience (Tedeschi & Calhoun, 2004). As people rebuild from a trauma, opportunities for social support and increases in physical self-perceptions can facilitate perceptions of growth. Specifically, social support can provide opportunities to self-disclose emotions and concerns (Calhoun & Tedeschi, 2006) which can help facilitate the growth process by reducing emotional distress. Furthermore, increases in physical self-perceptions can help shift the focus of thoughts from fear or anxiety about the trauma towards feelings of empowerment which may also facilitate growth. The types of growth which social support and increases in physical self-perceptions may facilitate include: the ability to develop closer relationships with others, discovering new possibilities in one's life, an increase in psychological strength, spiritual change, and new or renewed appreciation of life (Tedeschi & Calhoun, 2004). Much of the posttraumatic growth research conducted to date examines trauma that people could recover from to some degree, such as death of a loved one and diagnosis of cancer. But little work has been done with people who have experienced the trauma of diagnosis of a degenerative disease such as Parkinson's. Therefore, little is known about how people with Parkinson's may interpret their diagnosis and disease and whether they will experience posttraumatic growth given that they are aware they will inevitably worsen over time.

Participating in group physical activity may be adaptive for people with Parkinson's as it may provide opportunities to overcome physical challenges and be in a socially supportive environment through which experiences of posttraumatic growth may be facilitated. However, being in a group environment also lead to maladaptive experiences and outcomes, particularly for those who face the difficulties and uncertain future of living with a chronic illness. Therefore, the purpose of this research was to examine how people with Parkinson's disease experience social interactions and physical challenges in a group physical activity program, and what role they think those experiences play in posttraumatic growth.

CHAPTER 2. LITERATURE REVIEW

2.1 Physical Activity and Parkinson's Disease

Physical activity has been shown to elicit a number of positive outcomes in people with Parkinson's disease. Such outcomes include increased mobility and physical functioning (e.g., Combs et al., 2011; Hackney & Earhart, 2009a; Hackney & Earhart, 2009b; Hackney & Earhart, 2010), increased self-efficacy and competence (e.g., Cakit et al., 2007; Hackney & Earhart, 2010; Heiberger et al., 2011), and improved quality of life (e.g., Combs et al., 2011; Hackney & Earhart, 2009a; Hackney & Earhart, 2010). Furthermore, various forms of physical activity have been examined in those with Parkinson's, including tai chi, dance, resistance training, and high intensity training. Li, Harmer, Fitzgerald, Eckstrom, Stock, Galver, Maddalozzo, and Batya (2012) found that a 24 week tai chi program reduced balance impairments and falls, and improved functional capacity in people with Parkinson's. A series of dance studies conducted by Hackney and Earhart (2009a; 2009b; 2010) have shown that tango dancing can improve gait, balance, balance confidence, endurance, mobility, and quality of life in those with Parkinson's. Resistance training studies have found that progressive resistance training can improve muscle size, muscle strength, muscle endurance, and neuromuscular function (see David, Rafferty, Robichaud, Prodoehl, Kohrt, Vaillancourt, & Corcos, 2012 for a review). Finally, high intensity training studies have also been shown to be beneficial for people with Parkinson’s. For example, Canning, Allen, Dean, Goh, and Fung (2012) conducted a home-based high intensity treadmill training intervention with Parkinson’s patients and found that those in the treadmill group showed a greater improvement than the control group in fatigue at post-test and in quality of life at six weeks follow-up testing. Additionally, Ridgel, Peacock, Fickes, and Kim (2012) conducted an active-assisted cycling study using forced high intensity exercise (i.e., exercising at higher than preferred intensity) for those with Parkinson’s. The results showed an improvement in tremor and bradykinesia immediately following an exercise bout. It is clear from these studies that physical activity can elicit positive outcomes in those with Parkinson’s and should be considered as a viable treatment option.

2.2 Group Physical Activity

Previous research has found that people with progressive neurological conditions, including Parkinson’s, prefer to exercise in a group of people with the same or other disabilities, rather than alone (Elsworth et al., 2009). Group physical activity has been examined in many clinical populations, but one of the most extensively examined populations has been breast cancer. Sabiston et al. (2007) found that breast cancer survivors who were participants in a dragon boating team, found that being on the team facilitated social support from women with common challenges and a shared understanding of survivorship. Similarly, McDonough et al. (2008) examined the body image and social support experienced by novice participants in breast cancer survivor dragon boating teams. The findings showed that the benefits of social support in this program included connecting to women who implicitly understood the breast cancer experience and sharing first-hand information about living with breast cancer. Building on these two previous studies, McDonough et al. (2011) examined the development of social relationships, social support, and posttraumatic growth in dragon boating for breast cancer survivors. Participants who had positive social relationships and support within their team also reported enhanced posttraumatic growth. Most participants in these studies found the social interaction from other survivors positive, and enhanced their self-perceptions because it demonstrated survivors were capable of athletic achievement. However, for many participants, being in a group environment with other survivors, some who were doing worse off than others, also elicited fear of being reminded of their own mortality, fear of the possibility of recurrence, and fear of becoming close to others who may be lost through cancer recurrence. These fears led some participants to avoid the dragon boating team environment.

These examples of social support of breast cancer survivors in dragon boating may provide a foundation through which social support in group physical activity in other illness populations may be understood. Within Parkinson’s, specifically, previous research has suggested that satisfaction with social support is important as it is related to less psychological distress (Brod et al., 1998). Therefore being in a setting which can facilitate social support, such as group physical activity, may be valuable for those with this disease. Hackney and Earhart (2009a) showed that physical activity in a group setting provided improvements in perceptions of social support in people with Parkinson’s. This study consisted of assigning different dance interventions to people with Parkinson’s and found that tango dancing with a partner significantly improved social support and social interactions compared to the control group who did not receive dance lessons (Hackney & Earhart, 2009a).

Furthermore, this and other group physical activity studies have shown improvements in physical parameters such as gait, balance, and mobility, as well as psychological parameters such as self-efficacy and quality of life (e.g., Combs et al., 2011; Hackney & Earhart, 2009a; Hackney & Earhart, 2009b; Hackney & Earhart, 2010). Therefore, group physical activity may provide opportunities for social support and increases in physical self-perceptions in those with Parkinson's disease.

2.3 Physical Self-perceptions

Physical self-perceptions are how one describes and evaluates aspects of their body's appearance and its ability to successfully carry out tasks (Fox, 2000). These perceptions of the self in the physical domain are typically the most dominant contributors to self-esteem (e.g., Fox, 2000; Haugen, Safvenbom, & Ommundsen, 2011; McAuley, Blissmer, Katula, Duncan, & Mihalko, 2000). For example, decreased physical functioning has been linked to a reduced physical self-perception (Arbour & Ginis, 2008). Therefore, the perception one has of their physical self may be important to psychological well-being, and this may be particularly salient among those in clinical populations where the illness affects body appearance and ability to function.

Physical activity can help those in clinical populations improve their physical self-perceptions through providing opportunities to overcome physical challenges and demonstrate competence. For example, previous research by McDonough et al. (2008)

examined the psychosocial changes in breast cancer survivors across a season of team dragon boating and they found that participants perceived increases in physical functioning and physical competence which they viewed as important outcomes of their participation. Sabiston et al. (2007) also found that being on a dragon boating team facilitated posttraumatic growth through providing opportunities to overcome physical challenges. Within a population such as Parkinson's these perceptions of control and physical competence may be particularly valued as the body becomes 'uncooperative' and out of voluntary control over the course of the disease and this can be extremely disorienting (Habermann, 1996). By being physically active, people may regain a sense of physical competence through overcoming the challenge of controlling their body (Ravenek & Schneider, 2009).

Within the Parkinson's literature, only a few studies have examined physical competence in relation to physical activity. Cakit et al. (2007) showed an increase in self-efficacy to prevent falling in those with Parkinson's following incremental speed-dependent treadmill training. Heiberger et al. (2011) found that following a dance program, people with Parkinson's felt more positive about everyday competence, which included independence in activities of daily living and mobility. Hackney and Earhart (2010) found that tango dancing increased balance confidence in those with Parkinson's. Additionally, following a mountain walking program for people with Parkinson's, feelings of capability increased, and participants had an increased sense of endurance, and an increased sense of confidence in their ability to overcome their symptoms (Sunvissan & Eckman, 2001). These findings suggest that achieving physical competence though physical activity may be important for improving physical self-perceptions in those with Parkinson’s.

2.4 Social Support

Positive physical self-perceptions and physical competence may also be facilitated through social interactions with others. Social support has been shown to be an important resource for coping with stress (Lazarus, 1999) and important for initiating and maintaining physical activity (Vrazel, Saunders, & Wilcox, 2008). Specifically, perceived emotional support has been associated with better physical and mental health, and can buffer the damaging mental and physical health impacts of major life events and chronic strains (Thoits, 1995). Satisfaction with social support is important in helping those with Parkinson’s cope with the demands of the disease, and positively impacts psychological functioning (e.g., Brod et al., 1998; Pretzer-Aboff et al., 2009; Simpson et al., 2006). Previous research in clinical populations has found that social support received through group physical activity may provide opportunities for disclosure, allow people to act as sounding boards to help each other work through challenges, and provide role modelling of ways to positively cope with illness (e.g., Hefferon et al., 2008). Therefore, people with Parkinson’s may be able to receive social support through group physical activity that may allow them to disclose information about their experiences and have others to help them work through challenges, as well as be in an environment in which others with the disease may role model positive ways of coping with Parkinson’s, which may help increase feelings of competence.

2.5 Social Comparison

Past research has also indicated the potential for group physical activity in clinical populations to be an environment which can elicit negative experiences and emotions. For example Sabiston et al. (2007) found in their dragon boating study with breast cancer survivors that, for many participants, being in a group environment with other survivors, some who were doing worse off than others, elicited fear of being reminded of their own mortality, fear of the possibility of recurrence, and fear of becoming close to others who may be lost through cancer recurrence. These fears led some participants to avoid the dragon boating team environment.

These negative experiences may be explained, somewhat, by Festinger's (1954) social comparison theory which proposes that humans are motivated to develop stable, accurate appraisals of themselves and that particularly when objective standards by which to evaluate their attributes are unavailable, people often look to others as a standard for comparison. Three motives for comparisons have been examined: desire to affiliate with others, desire for information about others, and explicit self-evaluation against others (Taylor & Lobel, 1989). Using these motives, people will use upward or downward comparison to gain information, decrease anxiety, and cope with stressful events. In the original conceptualization of the theory, upward comparison involved individuals comparing themselves with other individuals they perceived to be better off than themselves in order to create a more positive self-perception (Suls, Martin, & Wheeler, 2002). Conversely, downward comparison involved individuals looking to another individual or comparison group who were considered to be worse off in order to dissociate themselves from perceived similarities and to make themselves feel better about their self or personal situation (Helgeson & Taylor, 1993). Taylor and Lobel (1989) suggested that affiliation and information tend to be sought from more fortunate others (i.e., upward comparison), while explicit self-evaluations tend to be made against less fortunate others (i.e., downward comparison).

However, the basic conceptualization in which both upward and downward comparisons would lead to positive self-perceptions did not take into account how social comparisons may also lead to negative self-perceptions. Therefore, Buunk et al. (1990) expanded on the original conceptualization by positing that how one feels in response to the information that another person is better off or worse off than oneself may depend on how one interprets the information. For example, learning that another is better off than yourself provides you with two pieces of information: (a) that you are not as well off as everyone, and (b) that it is possible for you to be better than you are at present (Buunk et al., 1990). Conversely, learning that another is worse off than you also provides two pieces of information: (a) that you are not as badly off as everyone, and (b) that it is possible for you to get worse (Buunk et al., 1990). Thus, if one focuses on the negative information presented in either situation, negative perceptions of the self may occur which could hinder the coping process. For example, Wood, Taylor and Lichtman (1985) found that individuals with chronic illnesses sometimes felt threatened by exposure to others who had the same disease as themselves, but who were more ill. This is an example of how downward comparison can lead to negative feelings about the self. Furthermore, meaning derived from a comparison is dependent on the likelihood of finding oneself at the target's level (Wood & Van der Zee, 1997). In other words, if a person is likely to reach the same level of functioning as the target in the future, for example, decline to a stage worse off than they currently are, they will likely focus on the negative information which may lead to negative self-perceptions (Carmack Taylor et al., 2007). This may be particularly relevant for those with Parkinson's given the degenerative nature of the disease.

People with chronic illnesses face stressful situations on a daily basis and being in a group setting with others who have the same illness may elicit different social comparisons which can have a variety of effects on self-perceptions and physical health (Arigo, Suls, & Smyth, 2014). Stanton, Danff-Burg, Cameron, Snider, and Kirk (1999) tested Taylor and Lobel's (1989) model in women with breast cancer and showed that participants demonstrated more positive self-evaluations after exposure to a poorly functioning target than to a well-functioning target with regard to both physical and psychological status. Also, the motive for upward affiliation was engaged when comparison attributes were open to personal control resulting in the desire to affiliate with well-adjusted others being stronger than the desire to avoid others with poor prognoses. Therefore, for those with breast cancer at different levels of health or adjustment, participants at all levels seemed able to socially compare in a way that achieved positive outlooks and growth.

For Parkinson's, however, the process of social comparison may lead to different outcomes given the progressively degenerative nature of the disease. In line with Buunk et al.'s (1990) proposition, when a person with Parkinson's sees another person with

Parkinson’s who is at a more advanced stage of the disease participating in physical activity with more difficulty than them, they become faced with what may be their future self. As a result, they may downwardly affiliate with those worse off which could hinder the coping process. Similarly, when those who are at a more advanced stage of the disease see someone at an earlier stage participating in physical activity with less difficulty than them, they may become faced with the self they have lost. Therefore they may upwardly dissociate from those better off, again, potentially hindering the coping process. Of course, there may also be ways in which those with Parkinson’s find a way to compare favourably to others using some of the same mechanisms found in those with cancer. For example, someone who is focused on their current condition, rather than projecting into the future, may be able to downwardly dissociate from those worse off and increase self-enhancement.

2.6 Posttraumatic Growth

Within a group physical activity environment, opportunities for improvements in physical self-perceptions and social interaction and may also facilitate positive outcomes such as posttraumatic growth. Posttraumatic growth (PTG: Tedeschi & Calhoun, 2004) is positive psychological change experienced as a result of the struggle with traumatic life experiences. In response to a traumatic life event, an individual is faced with challenges to their beliefs, goals, and the fundamental assumptions by which one lives. These challenges result in a process of rumination in which repeated thinking, reminiscing, problem solving, and trying to make sense of the event intrude during everyday activities (Tedeschi & Calhoun, 2004). Rumination is initially an automatic, intrusive process, but it can become increasingly voluntary over time following the trauma. As rumination becomes voluntary, it tends to also become more constructive in that it involves finding meaning in the event and identifying positive adaptations in the self (Calhoun & Tedeschi, 2006). For this shift to more controllable rumination to occur, one must disengage from untenable goals or assumptions held before the traumatic event occurred, while simultaneously persisting in an attempt to build new schemas, goals and meanings that incorporate the trauma and possible future events.

The integration of traumatic events into one's physical and mental schema is enhanced by social support. Helpful interactions with others in a social support system can provide opportunities to self-disclose emotions and concerns which helps individuals to process traumatic events (Calhoun & Tedeschi, 2006). Supportive transactions may further provide individuals with ideas for coping and validation of worth (Calhoun & Tedeschi, 2006). Through these mechanisms, social support can help facilitate the growth process by reducing emotional distress and helping to build new schema. As people rebuild from a trauma, the combination of opportunities for social support, rumination, and schema change can facilitate perceptions of growth through outcomes such as an increased sense of psychological strength, increases in the ability to relate to others, greater appreciation for life, increases in spirituality/religiosity, and the realization of new opportunities in life (Tedeschi & Calhoun, 2004).

Evidence of the five PTG outcomes have been documented in people who have undergone traumatic experiences. Specifically, changes in psychological strength can develop from the belief that surviving trauma will increase the likelihood of withstanding future difficulties (Tedeschi & Calhoun, 2004). Changes in the ability to relate to others have also been found in posttraumatic growth because individuals realize the importance of their relationships with people and this allows for the development of deeper and more meaningful relationships (Tedeschi & Calhoun, 2004). When the traumatic experience leads people to view life as a ‘gift,’ appreciation is often accompanied by a change in priorities as new values are assigned to experiences that were previously considered trivial (Tedeschi & Calhoun, 2004). Spiritual change is experienced as people engage more with fundamental existential questions following a traumatic event (Tedeschi & Calhoun, 2004). Finally, a heightened perception of the brevity of life following a traumatic event promotes a greater awareness of opportunity (Tedeschi & Calhoun, 2004). The diagnosis of illness prompted many people to reevaluate and change life goals, learn new skills, go back to school, and achieve new things (see Hefferon, Grealy, & Mutrie, 2009).

Parkinson’s is a disease which one may live with for decades. As symptoms progress, people may develop negative physical self-perceptions, and become isolated from the support of others which may lead to negative outcomes such as anxiety, depression, and lowered quality of life (Karlsen, Tandberg, Arsland, & Larsen, 2000). Participating in group physical activity may counteract some of these negative outcomes by providing opportunities to demonstrate control and physical competence, be in an environment in which one can receive support from others and use others for adaptive comparisons, and facilitate perceptions of positive psychological growth in those with Parkinson’s.

In line with these factors, the purpose of this study is to examine how people with Parkinson’s disease experience social interactions and physical challenge in a group physical activity program, and what role they think those relationships play in posttraumatic growth.

CHAPTER 3. METHODS

3.1 Methodology

In this study I used interpretative phenomenological analysis (IPA), a qualitative methodology developed to investigate how people make sense of major life experiences (Smith, Flowers, & Larkin, 2009). This methodology was developed in health psychology to capture the experiential aspects of people's lives (Smith et al., 2009). IPA has roots in phenomenology, hermeneutics, and idiography. Phenomenology takes the view that people understand their experiences in relation to their context, bodies and interpersonal relationships (Smith et al., 2009). Given that this study examined the experiences of social support and physical self-perceptions in those with Parkinson's in a group physical activity context, the phenomenological aspect of IPA was particularly appropriate. Hermeneutics refers to the interpretation of the explicit meaning of the participant's words, the context, and the researcher's understandings (Smith, 2004). IPA is doubly hermeneutic because it involves a dialogue between the participant who is interpreting their own experiences and the researcher who makes their own interpretations of the participants' accounts in light of their context, across multiple participants, and in light of extant theory. Idiography is concerned with the particular, for example, the experiences of people or cases within a specific defined experience (Smith et al., 2009). IPA is committed to grasping how particular experiential phenomena have been understood from the perspective of particular people, in a particular context (Smith et al., 2009). Consequently, IPA uses small, purposively-selected and carefully situated samples. Furthermore, the emphasis on the particular and the focus on understanding the meaning of something for a given person is not synonymous with a focus on the individual per se. Rather it is the experience itself that is of interest; therefore, idiography can be a process in which examination of a single case can move to a more general examination of an experience across cases (Smith et al., 2009).

Utilizing aspects from phenomenology, hermeneutics, and idiography, IPA is an inductive research approach that involves focusing on individual cases and then making interpretations across cases in light of existing theory and research (Smith, 2004). IPA has been utilized previously to examine the experiences of psychological growth in clinical populations who are involved in a group physical activity program (e.g., McDonough et al., 2008; McDonough et al. 2011).

3.2 Positionality

In interpretive methodologies, individuals are viewed as constructing their own truths and subjective realities through interaction with the world around them. In addition to the participant providing their interpretation of their experiences, as the researcher I also had a role in interpreting the data. Therefore, I must examine and acknowledge the assumptions and position I brought to the research.

Within this research, I brought a personal connection to Parkinson’s disease as I have both an aunty and uncle who suffer from it. Although I have not been around my aunty and uncle much in my life, and therefore have little direct experience with the disease, knowing that members of my family are suffering from it drove me to want to understand the experiences of the disease to a greater extent. My personal views are also influenced by the Maori cultural values I hold from my home country, New Zealand. Values such as whanaungatanga (building and maintaining relationships), tapu (sacredness), mahaki (humility), and mana (respect) are ingrained in my personal belief system. Whanaungatanga was particularly important to my research because it involved recognizing that relationships were fragile and needed to be nurtured (Moko Mead, 2003). My interests in this research also stemmed from a background in sport and exercise psychology. I have previously researched masters level and older adults' motivation for physical activity regarding their social relationships. In that research, I was interested in determining how social relationships can affect participation in physical activity and the behavior exhibited in older people in team sports. From this research, I came to understand that older adults' motivation for physical activity was influenced by the behavior of others in their environment, specifically, that when other in the environment act prosocially towards each other, motivation is enhanced. Through gaining this knowledge, I developed a desire to understand how social relationships in a group physical activity setting may impact the experiences of older adults whose participation in physical activity may be more difficult, specifically those who suffer from an illness such as Parkinson's. In conducting my current research, I have developed an awareness that social interactions experienced by those with Parkinson's in a group physical activity setting are complex and varied.

3.3 Participants

Twenty people (8 males, 12 females) who, at the time of recruitment were currently participating (*n* = 18) or had participated 12 months ago (*n* = 2) in an established community non-contact boxing program for people with Parkinson's were recruited. Exclusion criteria for this study included (1) those who did not have Parkinson's disease; and (2) those who were unable to verbally communicate in English. Participants had a mean age of 65.6 (*SD* = 6.47), were all Caucasian, and most were married or living with a partner (*n* = 17). Most had a postsecondary degree or diploma (*n* = 17), and median household income was between $80,000 and $100,000. On average, participants' diagnosis of Parkinson's had occurred 8.75 years before the start of the study (*SD* = 7.94). Participants had attended the program for an average of 4.15 years (*SD* = 2.06).

3.4 The Program

The program was founded in 2006 by a former district attorney who was diagnosed with Parkinson's at the age of 40. A few years after diagnosis, he began one-on-one boxing training with his friend who was an experienced boxer. He perceived a dramatic improvement in his physical health, agility and daily functioning. Consequently, he wanted to help others living with Parkinson's achieve the same results. The philosophy of the program is "Fighting back against Parkinson's." There are four levels of classes based on physical ability, considering both Parkinson's symptoms and fitness. Level 1 is designed for those with a high level of functioning, and level 4 is for those in an advanced stage of the disease in which one-on-one assistance from a caregiver is required to help with the activities. The training involves different types of exercises and activities ranging from boxing training (i.e., skipping, punching bags etc.) to resistance training, as well as stretching at the beginning and end of each session. Classes are 90 minutes in length and participants work at a moderate to high intensity throughout the session but may sit out any time they feel they need to. A total of 17 classes are offered Monday to Saturday and most levels are offered each day except Friday which is PD3 and PD4 only. Furthermore, Saturday has a combined level class in which participants from all level classes can attend.

All classes are run by certified boxing trainers who have a vast knowledge of Parkinson's disease. The head trainer was a professional boxer and fitness trainer who has been with the program since it was founded in 2006. The other two trainers joined the program in 2007 and 2011, respectively, both have family members with Parkinson's disease and both are certified personal trainers. The unique expertise and experiences of all three trainers enable them to collaborate with each other in training those with Parkinson's. The program also has a board of directors which includes a physical therapist, a neurologist, attorneys, and local community leaders who help to keep the program running and help to encourage further research with those who have Parkinson's. Recently, the program has developed a training camp in which the trainers teach others to become trainers using the boxing methods developed within the program. This is intended to enable the program and benefits to reach those with Parkinson's in different areas throughout the country and the world.

3.5 Procedures

Approval for this study was obtained from the university's Institutional Review Board. To recruit participants for the study, I contacted the program's trainers via email about the general purpose and procedures of the project, and requested permission to recruit members of the program for the study. Once permission had been granted by the trainers, I sent the trainers a recruitment email that was distributed to 130 members on their membership email list. The email gave members information about the general purpose of the project and asked those who wished to volunteer for the study to contact me by phone or email. I received 29 responses to the email and the first 20 participants who met the study criteria were selected for participation in the study.

When volunteers contacted me, I discussed the purpose and procedures of the study with them, answered any questions they had, and scheduled the first interview at a mutually convenient time. Interviews were conducted by myself and another experienced graduate student researcher in a quiet, private room at one of three locations: at the program's gym, at a public library, or in a university conference room.

At the beginning of each primary interview, participants read and completed a consent form. The purpose and procedures of the study were explained to each participant. Specifically, the audio recording procedure, confidentiality of the data, and the participant's right to choose not to answer any questions or to end the interview at any time were discussed. Participants were then asked to complete a short demographic questionnaire (see Appendix A). Interviews were audio recorded and lasted 30-90 minutes. A semi-structured interview guide (see Appendix B) was used to guide the interviews. The interview guide contained questions regarding participants' decision to join the program, their ability to do the exercises, the social environment, challenges or difficulties with participation, their perceptions of the impact of social relationships and support experienced, and changes they understand themselves to have experienced in life as a result of being in the program. In addition to the main questions, probes were used to extend the discussion and encourage participants to elaborate on their responses. At the end of the interview, the timeline for the follow-up interview was discussed and participants were thanked for their participation.

3.6 Data Analyses

Audio recordings were transcribed verbatim. I used NVivo V.10 (QSR International, 2012) to store and organize data for the analysis. Each case was analyzed individually, in order to first focus on each participant's interpretations of their own experiences. Each transcription was read through in order to gain a holistic view of that participant's individual experience. The transcript was then re-read and coded for the participant's interpretations related to the research question. Codes concerned language use, metaphors, and participants' understanding of the matters they discussed (Smith et al., 2009). Codes were labeled and reviewed by another experienced researcher, then similar codes were grouped into themes. Once this initial analysis was completed, participants were contacted by email to set up a time for the follow-up interview, this occurred approximately three months following the primary interviews. Follow-up interviews were conducted by phone (*n* = 17) or in person at the program's gym (*n* = 2) and lasted 7-15 minutes. I was unable to reach one participant for a follow-up interview. In the follow-up interviews participants were reminded of the voluntary nature of the study and were asked again for permission to audio record the interviews. Following this, participants were read a short description of the initial findings that pertained to them, and participants were asked how they believe the description of the findings represented their experiences. They were invited to elaborate and provide any additional information they felt was relevant. Participants were also asked a series of follow-up questions which prompted them to elaborate on things discussed in the primary interview. These questions were generated from and referred to information given in their initial interview. Questions addressed aspects of participants' experiences which could use further elaboration. Examples include asking about what contributed to changes in perceptions about the disease, clarifying what feeling 'better' meant, how support in the program has impacted their life now, and if feelings or thoughts expressed during the first interview still held true now. At the end of the interview, participants were invited to ask questions and were again thanked for their participation. The follow-up interviews were transcribed verbatim, coded, analyzed, and incorporated into the results.

I reviewed all transcripts for consistent coding. I then made a table of themes for each participant. Using participants' transcripts and table of themes, I wrote an individual narrative of each participant. This was in keeping with the idiographic roots of IPA which emphasizes the importance of the individual case first. Following this, myself and another experienced researcher proceeded to re-review each participant's transcript, table of themes, and individual narrative in order to identify and group similar narrative themes. In the process of grouping similar narrative themes, it became apparent that the types of experiences had by participants were more appropriate for grouping than the individual narrative cases themselves. Therefore, the grouping of types of experiences, rather than similar individual narratives, became the focus and the final stage of analysis involved writing a collective narrative of each type of experience.

3.7 Trustworthiness

In this study, quality was assessed using Smith's (2011) criteria for evaluating IPA. I strived to provide a clear focus for this research through posing a specific research question about social relationships, physical self-perceptions, and posttraumatic growth among people with Parkinson's involved group physical activity. Focus was further provided through using a semi-structured interview guide which contained questions regarding experiences of social relationships, physical self-perceptions, and posttraumatic growth in group physical activity. I attempted to obtain strong data through a thorough and careful interviewing process with each participant. These were conducted by myself and another graduate student researcher with interviewing experience. I also attempted to obtain strong data by following up with participants to allow for elaboration and clarification. I have strived to establish rigor through providing quotes from different participants and giving sufficient space to elaborate on each theme in the collective narratives. Furthermore, a discussion of convergent and divergent perspectives within each group has been provided to demonstrate patterns of similarity and uniqueness of experiences. Finally, I have attempted to craft carefully written, engaging narratives that convey the essence of the participants' experiences of social relationships, physical self-perceptions, and posttraumatic growth within group physical activity.

CHAPTER 4. RESULTS

4.1 Results

The results include: (1) a table of themes addressing physical ability, psychological challenges, social comparison, social support, and psychological outcomes; with a description of, and quotations exemplifying the themes; (2) a description of the similarities across the four patterns of experiences found; and (3) a narrative description explaining each of the four patterns.

4.2 Themes

The themes were placed into five categories describing the physical ability of participants, psychological challenges faced by participants in the program, social comparisons made by participants to other members, social support between members and trainers, and psychological outcomes from being in the program. The physical ability category included themes about improvements in physical competence that participants experienced through participation in the program as well as the physical challenges participants faced in doing the exercises. Often, these challenges were due to Parkinsonian symptoms and participants perceived a sense of control in perceiving that participation in the program would help to slow down the progression of these symptoms.

Table 1.1: Themes

Code	**Description**	
Physical Ability		
Physical competence	Improvement in physical strength and ability to do the exercises, being able to make accommodations to exercises that were challenging in order to continue being physically active, and being confident in their physical ability to do the exercises in the program.	*It's given me more confidence because it proves that I can do something like that, and I never would've, I worked out all my, well, most of my life and this is the hardest workout I've ever done, but, but I can do it every time. There's not been one time that I've come here and said, I can't do this.* (Gail)
Physical challenge	Difficulty with carrying out the training due to Parkinsonian symptoms, injury and fitness levels.	*Sometimes when the, when the meds don't work and everything, I have, I get dizzy and I have to sit down.* (Dawn)
Control	Feeling like one has the ability to actively improve their quality of life with the hope of slowing the progression of the disease by participating in the program.	*I wanted to do everything I could to delay, I think, keep active and delay if, if possible any progression.* (Fiona)
Psychological Challenges		
Fear of progression	Fear of disease progression forcing them to be put into a lower functioning class level, for example, level 3 or 4.	*I don't want the day to come when I can't. That bothers me because I want to be able to keep strong with what I think is making me stay strong.* (Jackie)
Hesitation about training	Reluctance about doing some of the exercises because of previous injury, or fear of falling.	*I tend to be more hesitant and less confident since I've fallen, uh, and hurt myself those other two times.* (Renee)
Apprehension about joining	Fear and apprehension about joining the program.	*I had all those kind of fears. Well, you know, what if it's like one of those classes you go into and the person at the front is saying, no pain, no gain, and you hurt yourself and then you can't do anything.* (Imelda)

Table 1.1 Continued

Social Comparison		
Downward disease affiliation: Fear of the future	Negatively comparing one's disease status to those worse off and fearing that they may be just as bad in the future.	*The very first class I went to, I cried, because I, I can see a lot of people and how they had, in a sense, deteriorated, you know, and I thought, that's gonna be me.* (Olive)
Downward disease dissociation: Feeling good about their current condition	Positively comparing one's disease status to those worse off.	*I'm pretty blessed that my Parkinson's is, uh, um, is not as progressed as most people.* (Hayden)
Upward disease affiliation: Hope for the future	Positively comparing one's disease status to those who seem to be doing well for their stage of the disease and being hopeful that they will be doing well when they reach that stage of the disease.	*When you talk to other people then, that have been doin' this, like, [Marty] for thirteen years and she's in my class and they're doin' better than me, much better than me…I think, we'll see, you know, there's a good possibility that thirteen years from now I might be where I am.* (Belle)
Upward disease dissociation: Feeling bad about their current condition	Negatively comparing one's disease status to those better off.	*You almost wouldn't know he has Parkinson's. And that's when you're reminded that you do have a problem.* (Norah).
Downward ability dissociation: Feeling good about their training ability	Positively comparing one's ability to those with worse ability.	*I'm still able to do more than a lot of the other people in the class and so that makes me feel good.* (Esther)
Upward ability affiliation: Inspiration	Positively comparing one's ability to those with better ability and being inspired to reach that level of ability.	*I saw people that were further advanced than I was doing it and I thought, well, if they can do it, I can do it.* (Albert)
Upward ability dissociation: Feeling bad about their training ability	Negatively comparing one's ability to those with better ability.	*They started me out in PD 3. Then they said I can move up to 2 if I wanted to. PD 1 and 2 are better and those guys can really jump rope and they, I wasn't comfortable. I wanted to not stand out as being the, always last.* (Norah)

Table 1.1 Continued

Social Support		
Giving support	Being able to give back to their fellow participants, often those who are worse off.	*I just kinda take it upon my, you know, if I see somebody not doin' what they, you know, need to be doin' or goin' in the wrong direction, I, I just feel like I should help out*. (Albert)
Informational support	Receiving information about symptoms, medication, and experiences from others.	*We have discussed, like, the drugs that we have got and side effects etc.* (Meredith)
Personal assistance	Receiving physical help to do the exercises in the program, as well as others modeling ways in which one could adjust to challenges in the exercises.	*Everyone helps everyone put, like, gloves on. Ah, some of them will help me, when I try to get in the ring, they'll hold the ropes up, you know, just things like that.* (Belle)
Emotional support	Others being caring, loving and encouraging.	*When they hug you, you really feel like they love you and they care about you.* (Lance)
Task challenge	Other participants and the trainers pushing one to challenge oneself by working hard.	*When I started, my left side was noticeably weaker than my right side. Um, when I boxed, they're always pushin' me to hit with my left hand, they know that that's really what I need to develop.* (Quentin)
Task appreciation	Other participants and the trainers acknowledging and appreciating the efforts put forth by oneself.	*Well, one o' the nice things about the people here, they know how to compliment people…Congratulating people when they do well. "Thata boy", type thing.* (Toby)
Listening support	Feeling listened to by others without judgment.	*Everybody is, without fail, friendly, accepting, "how you doin'?" You know, willing to listen to, to you.* (Kyle)
Reality Confirmation	Interacting with others who understand the disease and help confirm one's perceptions of the world.	*Here, I'm with people that are in the same boat that I'm in.* (Hayden)
Camaraderie	Getting along with others, developing friendships and sharing humor with other members and the trainers.	*We all do things together and we have, we just get along with everybody.* (Dawn)

Table 1.1 Continued

Psychological Outcomes		
New possibilities	Expressing surprise at their ability to do things and having a newfound confidence to try new things outside of the program that one had not done before, or had given up long ago.	*It just gives you an all over good feeling that you can, you can do it and, uh, I would never have thought, before I had the Parkinson's, that I could do anything like this.* (Silvia)
Relating to others	Forming close relationships and connections with other members and being more open talking about Parkinson's to other people.	*I'm just more willing to acknowledge that I have Parkinson's, more willing to answer questions about it, talk about it. More open, um, comfortable being open about it, whereas before, I was not.* (Cliff)
Appreciation of life	Living in the present and being optimistic about the near future.	*Talking with others and seeing how others are affected in that way makes me realize I need to be doing some of these things now… it's changed my sense of urgency and, meaning that, something I was gonna do someday, I'm bumpin' it up.* (Esther)
Personal strength	Being emotionally stronger and able to cope with challenging and stressful situations.	*I think it helped me be stronger and, and then realize if I've overcome Parkinson's, got-, gotten better with having Parkinson's, then, then I can overcome [major illness] too.* (Gail)
Perceived symptom improvement	Perception of symptom improvement and feeling a sense of decline when workouts were missed.	*I feel less symptomatic. I mean, I feel, I feel less like a person with Parkinson's.* (Percy)

The psychological challenges faced by participants were centered around aspects of the disease. Participants feared joining a program which was unfamiliar and where they may hurt themselves because they did not know how to exercise. Many were particularly fearful of the exercises because of difficulties with motor symptom and this led to hesitation with some aspects of the training. Furthermore, once participants had been in.the program for some time, had developed friendships with other people in their class, and sensed improvement in their symptoms, many participants feared progression of the disease, which they knew to be inevitable, forcing them to be put in a lower functioning class.

The social comparisons participants made with others varied based on disease and ability, and resulted in both positive and negative emotions. Many participants downwardly affiliated with those who were worse off in the disease when initially entering the program but these comparisons often changed after developing close relationships with the people to whom they were comparing. Participants were able to change their focus of comparison to more controllable aspects such as performance and ability rather than comparing on uncontrollable aspects of the disease. This allowed many to change how they viewed their future, from fearing progression to hoping for a good level of physical ability when further advanced in the disease.

The social support themes centered around the varied types of support given and received by participants. For some, giving support to others was an important part of their experience in the program as it allowed them to develop mutually supportive relationships and achieve a sense of fulfillment in their lives. There were many different types of support both given and received by participants. Much of the support received had an affective component as participants appreciated being encouraged and pushed in their work outs, listened to, and cared for. Furthermore, being able to interact with others who understood the disease and could discuss it on a personal level was also a valuable source of support for participants.

The final category of themes, psychological outcomes, were the changes participants went through and what they achieved through participation in the program. Many of the outcomes were aspects of positive psychological growth in line with posttraumatic growth theory. Being in the program and improving in physical competence allowed many participants to express surprise in their ability and a new-found confidence and realization that they have new possibilities to do things in their lives. For some participants, receiving support from others who understood the disease and shared information about it enabled them to open up and feel that they can relate to others about the disease. Personal strength was achieved for some through both increases in competence and receiving support from others as they felt that both aspects helped them cope better with challenging situations. Many participants also perceived outcomes more specific to their disease manifestation, such as perceiving symptom improvement through being in the program and this encouraged many to adhere to it with the belief that it was slowing the progression of the disease

4.3 Collective Narratives

4.3.1 Similarities Across Narrative Experiences

Some experiences were shared by all participants. These experiences included a desire to control Parkinson's through physical activity, receiving unexpected support from others in the program who understood the disease, and developing feelings of competence through participation in the program.

All the participants in this study joined the program out of the desire to control Parkinson's and slow the progression of the disease through physical activity:

> "I had lost a lot during that four to five years, uh, physically and hadn't exercised intentionally for years. So I just felt that I would have a real opportunity to take better care of myself and perhaps delay the onset of the disease." (Lance)

Most participants had prior knowledge of research which suggested that physical activity could positively impact symptoms and many had either been referred to the program by friends or family, or had seen it discussed in the media. Some had even been in a support group with the founder of this program and knew his story personally.

> "There were some people doing some studies and it came that exercise may be beneficial, since then there've been more definitive results to indicate it is beneficial, it definitely is beneficial. Um, [founder] just, you know, talked about,

> I mean, what a difference it made to him and to his symptoms and so, that's really got, what got me to go initially and to continue to go." (Esther).

Furthermore, the program reinforces the effects that physical activity can have on symptoms and promotes the program as a way to enhance overall quality of life in those with Parkinson's disease. Although the program does not mention slowing the disease progression, specifically, many participants felt that working out in the program was slowing down their progression, and they valued this feeling, even if it was just a perception that they had: "I think it is the movements and the constant exercise and things like that that, even if it's psychological that it's ok, cause I feel better when I do it." (Gail).

Within the program the participants also realized that they received a unique source of support from those who could understand the disease:

> "I think the support in [the program] has a little, little different quality to it because of fellow travelers. I think it's even more, more impor'nt than the support that I get from my wife…I don't think she really understands the way they understand." (Cliff)

These were people they could discuss their symptoms and medications with, who they felt they could be themselves around, and who encouraged them during the workouts. Many participants expressed that outside of the program, people who did not have the disease could not fully understand what they were going through and therefore could not provide the same level of support that others with Parkinson's, for example, those in the program, could provide. However, the support and understanding participants received in the program was not only from other members, it was also received from the trainers who did not have Parkinson's:

> "I don't know how someone can understand how a Parkinson's person feels without having it as much as they [the trainers] do… they come as close to being empathetic, they're not sympathetic, they're empathetic." (Norah).

The participants valued the trainers' knowledge and empathy for people with Parkinson's and they felt a special connection with them which enabled them to feel comfortable and confident in the trainers' abilities to help them achieve success in the program.

Participation in the program also led all participants to improve their perceptions of competence through improving in the exercises:

> "I started out barely knowing how to jump rope. And now I, you know, I started out only being able to jump on one foot, so right foot, right foot, left foot, left foot. Now I can jump rope both feet and I can go forwards and backwards," (Imelda)

Many participants were surprised at their ability to do the work outs in the program and realizing that they had abilities they did not know they had allowed many participants to feel a sense of pride and achievement: "I'm kinda proud of the fact I can do it. It, it instills a sense of, um, accomplishment" (Lance). These feelings encouraged participants to continue on in the program and gave them confidence in their ability to do things outside of the program:

> "I no longer ask my children to come over and do for me, uh, I do all my chores around the house, I do all my yard work and everything. I don't have my boys comin' over to cut my grass. If there is, uh, home repairs, I do 'em. I work on my cars that I have… it's given me back a lot of, uh, pride and a lot of ownership of, of who I am." (Hayden).

Although these similar experiences were common among participants, there were differences in how they played a role in the patterns of narrative experiences of participants. A narrative description of each of the four collective patterns of experience appear below. The four cases were labeled based on quotes which exemplified the general pattern of each narrative: (a) "You can be yourself there"; (b) "When I'm on the good days, it's like I was never ill"; (c) "We all make jokes"; and (d) "Volunteering…a tremendous gift."

4.3.2 "You can be yourself there"

Several participants began with a fear of evaluation and a wish to keep Parkinson's diagnosis a secret from others out of a sense of embarrassment and fear for what telling the truth may do to their career. Though the roads which led to joining the program were different, including referral from doctors, seeing the program in the media, and actively searching for a physical activity program for people with Parkinson's, they had one shared expectation: that the training would help to minimize their symptoms: "My hands wouldn't, uh, work very well sometimes, like writing and playing the piano and things like that, so I thought it would help," (Olive). In the past, they had downwardly affiliated to those worse off and this led to fear of seeing what their future selves may be: "It makes you feel worse because you see, what could, you could be down the road," (Silvia). Although this affiliation produced negative feelings about the perception of their future self, they had also used downward dissociation comparison by comparing favourably to others with worse symptoms than their own in order to regain a positive view about their own current condition: "There's a lot of people worse off had Parkinson's with half as much time as I have and so then again, those things, those things felt very good, very positive," (Cliff). As the participants continued to attend the program and work out in close quarters with others who have the disease, they came to realize that the program was a highly supportive environment where they were encouraged during workouts, felt cared for and listened to, and where they could gain information about symptom experiences and medications. They valued this support from others who understood the disease and it allowed them to feel comfortable and open up about their disease and its manifestations in the program environment: "You can come to [the program] and…they know how you feel and you can be yourself there," (Gail). As the support from others encouraged them to continue to attend the program, the participants improved in doing the training exercises and felt their physical competence and confidence increase. Through these increases in confidence and Parkinson's specific support, these participants experienced a perception of new possibilities in their lives "It just gives you an all over good feeling that you can, you can do it and, uh, I would never have thought, before I had the Parkinson's, that I could do anything like this," (Silvia). They also experienced an increased ability to grow closer to and relate to others: “You got to know the people…to learn about their problems…to grow closer to the people in terms of their personality and their needs,” (Quentin). Despite their increased comfort within the program, however, they continued to fear evaluation from those outside of the program and attempted to hide their symptoms when in the outside world: “I make sure my medicine’s adjusted so my symptoms are not showing prominently. I try to conceal my symptoms [in public].” (Cliff).”

For some, feeling comfortable within the program and with their own current condition required more than downwardly dissociating from those worse off and receiving support from those in their class. Some people began the program in a class in which they felt others were much worse off than them and they felt they did not need as much help as others doing the exercises: “I don’t need any help, I know what to do,” (Albert). After some time in which they improved in the exercises, they moved up a class level to where they felt they were more similar to others and belonged. Being around others they felt more similar with, allowed them to feel comfortable about their own condition and encouraged them to continue to work out and improve their physical abilities:

> “I got into a different class, you know, a higher class, I should say, a class that was the hardest, um, not far along in their, in their diagnosis. So it helped give me a little bit more encouragement,” (Olive).

4.3.3 “When I’m on the good days, it’s like I was never ill”

Several participants felt that others outside of the program misunderstand and misjudge their symptoms. As they entered the program, their first instinct was to downwardly dissociate from those worse off, believing that their own misunderstood symptoms were not as bad as those whose symptoms were more severe: “Some people have terrible tremors and mine aren’t too bad really,” (Belle). However, they also became fearful thinking about what their future selves may be: “Seeing how others are affected…I can sort of see my future in some of those people,” (Esther). As time passed and these participants grew closer to, and gleaned important information about symptoms and coping from those worse off, they became inspired seeing these same people pushing through and overcoming their symptoms to succeed in their workouts:

> “[Rob] can’t do everything that all of us do because he’s, sometimes he’s symptomatic…he freezes and, um, so sometimes he struggles to get up to the bag but…when he gets there it just blows me away cause I’m thinkin,’ how can he do that when he just struggled to get up to the bag?” (Lance).

Those who were initially viewed as worse off became role models with whom participants could positively affiliate by thinking about what their own future selves may be able to physically accomplish at that stage of the disease:

> “When you talk to other people then, that have been doin’ this, like, [Patricia], for thirteen years and she’s in my class and they’re doin’ better than me, much better than me. Uh, she doesn’t walk as well as me, she doesn’t talk as well as

> me, but she's exercisin' better than me. So I think, we'll see, you know, there's a good possibility that thirteen years from now I might be where I am." (Belle).

This positive affiliation motivated participants to continue to attend the program and to persevere in overcoming the physical challenges they faced with their own symptoms: "I saw people that were worse off than I and I thought, well, maybe I can. So, I learned to jump rope," (Renee). Pushing through in the work outs with the support of others in the program allowed them to feel an increase in pride and confidence, as well as the perception that their symptoms were improving: "I feel less symptomatic. I mean, I feel, I feel less like a person with Parkinson's, I feel more like a normal person," (Percy). These feelings allowed them to realize that, although some symptoms may be more difficult to overcome than others, they can focus on making the most of 'on' days and dealing with symptoms they can control: "When I'm on the good days, it's like I was never ill…my approach is to make as much outta, make as much as I can out of what's there and not get all upset about off days," (Toby).

4.3.4 "We all make jokes"

Many participants initially had mixed feelings about joining the program: they had both anxiety and apprehension about joining, and a desire to join in order to take control of the disease. The anxiety and apprehension grew out of fear about meeting others with Parkinson's, being unsure about their physical abilities to do the training, and going to an unfamiliar place: "The biggest thing that I fight is the anxiety…anything new, um, going to a new place," (Norah). As they faced these uncertainties, they found that, within the program, they were in an environment with people who understood the disease and shared jokes about symptoms and medication side effects: “I joke and facetiously tell people that I’ve ruled out a second career in Swiss watch repair or hand grenade construction,” (Renee). Where these jokes about Parkinson’s would be seen as taboo and uncomfortable for those outside of the program, within the program, breaking the taboo by sharing this type of humor helped to alleviate some of their anxieties about the disease as they felt that, within this environment, everyone was part of a shared, equal connection: “We all make jokes, say, say a joke or whatever, but, you know it fits. You feel, you, you feel like you’re equal to everybody,” (Dawn). Feeling comfortable being able to share Parkinson’s humor with others created a unique, fun environment which participants enjoyed being in and this encouraged them to continue to attend and work out in the program: “Those are things that really, um, give a person a sense of belonging and encouragement to go on to make an effort to accomplish something new.” (Fiona). Through continued attendance, they were able to gain confidence through overcoming the physical challenge of the work outs and overcoming their anxieties through feeling that they were stronger not just physically, but mentally and emotionally as well: “I’m stronger mentally, I’m stronger physically, um, I’m definitely stronger emotionally.” (Meredith).

4.3.5 “Volunteering…a tremendous gift”

Some participants feared evaluation by others. Evaluation of their physical abilities was experienced as threatening to these people because they joined the program not only to control the disease, but because they also highly valued physical activity in their lives, and were striving to maintain a sense of athletic identity: “I was a runner…I wanted to make sure I, I stayed fit cause I wadn't able to run the distances that I was used to," (Kyle). These participants had been physically active most of their lives. Therefore, using physical activity as a way to help cope with the disease provided a feeling of comfort and familiarity: "I was always an athletic lady and I always did athletics things and stuff like that and, I just had to have somethin' to do and somethin' to keep me goin'," (Dawn). These were physically competent people who relished competition and pushing themselves in the work outs and although they focused on the physical aspect of the program initially, they came to find that they were in an environment with like-minded others who would push through in challenging times and push them through competition and words of encouragement: "It's good to find a group of people that are dealin' with the same thing, that are, you know, they're not ready to throw in the towel, so it's a pretty fun group to be around," (Kyle). Being in this environment reinforced the value of physical activity as they perceived improvement in their symptoms and a feeling that, without the program, they would be in a worse off state:

> "I think that if I had not been going down there, I wouldn't be able to do things I do now because…they teach agility, I, you know, balance…I don't think I'd be as mobile as what I am now if it wasn't for them," (Albert).

Furthermore, the support received from others which helped them to achieve in their work outs imparted a desire to give back to those whose symptoms were worse than their own as they wished to help others achieve the same feelings of success that they had gained within the program:

> "Even though I'm here to, for myself, I feel like I also can give back to other folks that are here so it gives me a chance to serve other folks as they're handling it instead of just always taking," (Hayden).

Helping those in the lower functioning classes was a valued experience for these participants because they could help others to succeed and be inspired by the accomplishments of those at a later stage of the disease than themselves:

> "The four level, I volunteer at that one…that's been a tremendous gift to me…it's really neat, the, uh, the people I've helped by, you know, helping with activities and makin' sure they're maintainin' their balance, and so on," (Kyle).

Through this experience, participants' evaluation fears were reduced as they realized that having visible motor impairments did not prevent them from being able to succeed physically. Having fewer evaluation fears allowed them to feel more comfortable with their Parkinson's and this encouraged them to open up and relate to others: "I can now, I feel I can open up to people, you know? Um, I came to grips with it. I've got Parkinson's, it doesn't have me," (Hayden).

Although the desire to help others was a conscious and deliberate choice by some, others found that the desire to help others grew out of attending a class that was a convenient time for them. Some travelled to the program from far away and could not make the classes to which were the best fit for their level of ability. Therefore, they attended whichever class they could fit in to their schedule, often attending a class of lower level than their ability. Despite their place in that class beginning out of convenience, these participants found that they came to value their place as they felt they should be there to help those who were worse off with their work outs, regardless of what class they were more suitable for based on their level of ability: “I help out some of the other people that get confused and like that so…I feel like I need to be in that class to, to try and help them out,” (Albert)

CHAPTER 5. DISCUSSION

5.1 Discussion

The results of this study suggest that there are multiple experiences of social interaction, physical challenge, and posttraumatic growth among people with Parkinson's disease involved in group physical activity. A common and important experience of all participants in this study was the expectation that participating in the program would improve their symptoms and maybe even slow the progression of the disease. Furthermore, there were four narratives of experiences characterized by (1) finding a safe space in the program; (2) perceiving improvement in symptoms through self-regulation despite loss of control; (3) anxiety relief and creating an in-group and shared social connection through shared humor with others who have Parkinson's; and (4) focusing on helping others in lower level classes. The findings of this study provide insight into the ways in which participating in group physical activity may be beneficial for those with Parkinson's and may provide useful information for how to structure an adaptive group physical activity program for those with degenerative diseases such as Parkinson's.

All participants in this study had expectations that the group physical activity program would improve their symptoms, and many even hoped it would slow the progression of the disease. Previous research by O'Brien, Dodd, and Bilney (2008) examined the motives of people with Parkinson's participating in a community-based group resistance exercise program and found that participants had expectations that participation would minimize the impact of disease progression, either by improving strength and activities of daily living, or by slowing down their loss of function. Many participants went on to note positive changes in strength, fitness, fatigue, hyperkinetic movement, and function following participation in the program. Given that individuals will progress in the disease at different rates, there is no definitive way to determine whether physical activity can actually slow the progression of the disease. However, it seems that what is most important is that participants may perceive that physical activity is slowing down their progression. This perception may be gained through increases in physical strength and fitness, and improving motor and non-motor symptoms, which have been shown to be outcomes achieved through physical activity in those with Parkinson's (e.g., Combs et al., 2011; Hackney & Earhart, 2009a; Hackney & Earhart, 2009b; Hackney & Earhart, 2010; O'Brien et al., 2008). Therefore, people with Parkinson's may enter a group physical activity program with the expectation that participation may lead to improvements in the disease and continued participation may provide them with perceptions of fulfilling that expectation through physical improvements which are commonly experienced through physical activity, such as increases in strength and fitness.

As Parkinson's disease progresses, motor symptoms such as freezing and bradykinesia can become difficult to control and side effects of medications such as dyskinesias may be visible to others. The uncontrollability of symptoms can be an embarrassing experience because it can elicit stigmatization from others due to negative societal perceptions of bodily movement (Joachim, & Acorn, 2000). The more visible and less ‘normal’ the symptoms of Parkinson’s are, the more likely they are to be judged as socially unacceptable or threatening by people who do not have Parkinson’s (Joachim, & Acorn, 2000; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). In order to avoid these feelings of embarrassment with visible symptoms, people with Parkinson’s often try to conceal their symptoms or retreat from public life (Bramley & Eatough, 2005; Joachim, & Acorn, 2000) which can result in social isolation and psychological difficulties such as depression (Simpson, McMillan, & Reeve, 2013). Within this study, participants found that the fear of negative evaluation or stigmatization they commonly felt around strangers in public disappeared when they were introduced to others in the program who suffered from the same disease. Instead, they found that these others with Parkinson’s were not ashamed to be visibly symptomatic within the program environment and the confidence they had in displaying their symptoms allowed the participants to feel that they, too, could show their symptoms without fear of judgment and be themselves in the program environment. Previous research attests to the notion that during times of stress, people prefer to seek the company and support of others who are in a similar situation (Davison, Pennebaker, & Dickerson, 2000). Being around others who are in a similar situation of stress, for example, those who have the same disease, may elicit sharing of experiences, discussions of coping strategies, symptoms, struggles, medications, and how the disease affects them physically, psychologically and socially, as has been shown in previous research with support groups for Parkinson’s (e.g., Attard & Coulson, 2012). Furthermore, research by Birgersson and Edberg (2004) has shown that people with Parkinson’s in group rehabilitation felt that being with others in the program who had Parkinson’s reduced their feelings of alienation and that sharing their experiences with others in a similar situation seemed to strengthen their own identity and increase their sense of belonging. This finding suggests that group physical activity may provide an environment in which those with Parkinson's can feel safe from stigmatization and share valuable experiences with others which may allow them to be comfortable working out and showing their symptoms to similar others.

Given that Parkinson's is a progressive disease, symptoms will inevitably worsen over time. For many, this progression results in a loss of control of simple motor functions which cannot be regained (Stern, 1990). People with chronic conditions such as Parkinson's are often faced with loss of control; however, research suggests that those living with a chronic condition may be able to psychologically adjust their perception of control by focusing on improving aspects of the illness that one can control and yielding control in domains that cannot be changed or controlled (Frazier, Cotrell, & Hooker, 2003; Leventhal, Leventhal, & Cameron, 2001). For the participants in this study, the process of being able to adjust their perceptions was largely influenced by comparisons to those worse off with the disease. When initially entering the program, some participants affiliated with those who were worse off than themselves and this elicited a feeling of fear of advancing to the same level of progression in the future. However, after realizing that the people they were comparing with were overcoming physical challenges despite their worsened disease condition, the participants developed hope that they, too, would be able to overcome the same physical challenges if and when they advanced to that level of progression in the future. This reconstruction of their future self-image reflects a self-regulatory process (Frazier et al., 2003) whereby they refocused their perceptions of control to areas that they could improve on, such as physical ability in physical activity, and let go of focusing on control of the progression of the disease itself. McDonough et al. (2008) provide an example of such a cognitive shift in breast cancer survivors who participated in dragon boating with other survivors. Many of the participants shifted their focus from bodily appearance aspects such as weight loss, that they had difficulty controlling due to side effects of treatment, to athletic identity during their participation. These findings suggest that being in a group physical activity environment may afford people with Parkinson's the opportunity to see others who are role modelling adaptive coping during advanced stages of the disease through being physically active. Seeing these role models may elicit positive comparisons and give hope for the future functioning of participants despite knowledge of inevitable disease progression.

Participants in this study overcame anxiety through sharing jokes about Parkinson's with other members. Previous research has suggested that humor can decrease cognitive anxiety (Bennett & Lengacher, 2008; Crawford & Caltabiano, 2011) and may mitigate adverse effects of stress (Abel, 2002; Bouskill, 2012) because the mood-repairing effects of humor may be mediated by cognitive processes (Strick, Holland, van Baaren, & van Knippenberg, 2009). Specifically, the ability to shift and maintain a humorous outlook on life may enable individuals to distance themselves from negative situations (Strick et al., 2009). From this perspective, it has been suggested that humor should be most effective in reducing negative emotions when it matches the stressor as it provides a way for individuals to reappraise the situation from a new and less threatening point of view and this has been shown in breast cancer survivors in a support group setting (Bouskill, 2012).

Therefore, by being able to joke about Parkinson's, which is likely to be a large stressor in the participants' lives, they are able to reappraise the disease and their symptoms from a new point of view. Furthermore, in people with chronic illnesses such as Alzheimer's, humor has been used by support group members to normalize each other's impairments (Lyman, 1998), and it has been suggested that humor coping may influence a person's experience of their disease, even though it does not directly affect progression (Merz, Malcarne, Hansdottir, Furst, Clements, & Weisman, 2009). Humor may influence the experience of the disease through creating solidarity and building a shared social identity with others (Kuipers, 2008) where making jokes about a topic that would be viewed as taboo outside of the, for example, program environment, is accepted and encouraged within that environment. Therefore, for the participants in this study, sharing humor about the disease with others in the program may have positively influenced their experience of Parkinson's by helping them to reappraise their symptoms as normal and become part of a shared identity which helped to decrease their anxiety about the disease. It seems that being in a group physical activity environment with others who are facing the same disease stressors may provide opportunities for people with Parkinson's to reappraise and normalize their old and new symptoms and create opportunities for shared connection through sharing jokes about the disease and how it affects their physical activity.

The act of giving support by helping others was a valued experience for many participants, particularly those at an earlier stage of the disease. The fulfillment gained from helping others with similar illnesses has been shown in previous research with breast cancer survivors in dragon boating (McDonough et al., 2011). Additionally, altruism, the act of getting pleasure from helping and giving to others (Vaillant, 2000), has been used as a coping strategy in those with HIV as these people reported reaping personal benefit and meaning in their lives from helping others in the HIV community (Reeves, Merriam, & Courtenay, 1999). Furthermore, previous research has suggested that the salience of shared group membership will give rise to altruism and prosocial behavior (Vollhardt, 2009). Group membership is determined by two factors: similarity and common fate. Similarity is identifying common factors one has with others, while common fate refers to the same or shared experience (or anticipation) of harm (Vollhardt, 2009). Previous research has suggested that common fate gives rise to a sense of 'we-ness' which in turn predicts prosocial behavior (Vollhardt, 2009). Within the current study the experience of helping those with whom participants shared a common fate may have added meaning to participants' lives by providing a sense of fulfillment. Furthermore, the desire to help others may have been motivated, at least in part, by the expectation that others would provide the same help for those participants if and when they, themselves, reach a more advanced stage of the disease. These findings suggest that being in a group physical activity environment with others who have the shared fate of Parkinson's disease may allow people to add meaning to their life by helping others they identify with and this may also fulfil an expectation that others will do the same for them when they have advanced further and need help with being physically active themselves.

The reported changes in social comparison processes used by participants throughout their time in the program were also of note. Previous research suggests that upward and downward comparisons can be undertaken for a number of reasons, for example to increase self-enhancement or improve self-evaluation, and given a variety of meanings, such as feeling good that one is doing better than others or feeling badly that one is doing worse than others (Carmack Taylor et al., 2007). The motives for upwardly or downwardly comparing to others and the meaning given to such comparisons depends on the context and the target of the social comparison (Bardel, Fontayne, Colombel, & Schiphof, 2010; Blanton & Stapel, 2008). Sparkes, Perez-Samaniego and Smith (2011) suggest that changes in social comparison have been used to manage emotions and give meaning to one's changing condition in those with cancer. Typically, research has shown that those with cancer tend to dissociate from those worse off and will sometimes try to avoid interacting with those worse off all together (Carmack Taylor et al., 2007; McDonough et al., 2011). Instead, those with cancer tend to affiliate with those who are doing better in order to maintain self-enhancement, particularly if they have hope that they can reach the upward target's level of health (Carmack Taylor et al., 2007; Van Der Zee et al., 2000). For the participants in this study, however, social comparisons tended to be towards those who were worse off. Unlike cancer, from which one might recover to some extent, Parkinson's is a progressive disease with no cure, and the certainty that one will degenerate over time. It could be that for those with a degenerative disease such as Parkinson's, knowledge of impending decline makes downward comparisons more important than upward comparisons as the likelihood of reaching the target is greater (Buunk et al., 1990). Furthermore, it is possible that patients from distinct illness populations use social comparisons in different ways and/or for different goals (Arigo et al., 2014). Therefore, finding a way to positively affiliate with those worse off by focusing on successes made by these targets may have been a way participants managed their emotions and gave meaning to their condition by providing more hope for their future self, rather than fearing their future self. These findings suggest that group physical activity programs may provide an environment in which those with Parkinson's may have opportunities to see others at different stages of the disease being physically active and use social comparison to increase self-enhancement.

5.2 Limitations

Limitations of this study included the use of two researchers to conduct initial interviews and participant demographics. During this study, two researchers conducted interviews during data collection. Using a second researcher was necessary in order to conduct interviews in a timely manner given the significant travel distance from the university to the gym that housed the program. However, having a second researcher conduct some of the initial interviews prevented me from building a rapport with those participants which may have affected how they interacted with me during the follow up interview. The first encounter with a participant is an important rapport-building opportunity as it initiates building a research relationship that will allow the researcher access to that person's story (Liamputtong & Ezzy, 2005). Participants may not have been as forthcoming and open about their experiences with me because they had not been given the opportunity to meet and become comfortable with me during that first interview. Another limitation was that the participants in this study were all Caucasian, and most of middle to higher socioeconomic status. Research has shown the increasing prevalence of Parkinson's in a variety of race and ethnicities, as well as people from different socioeconomic statuses (Van Den Eeden, Tanner, Bernstein, Fross, LeimPercy, Bloch, & Nelson, 2003). Therefore, future research should look into Parkinson's populations of those who are from different races or ethnicities as well as different socioeconomic statuses to better understand the role group physical activity plays in the experience of physical self-perceptions, social comparisons, social support, and posttraumatic growth of those from different social and cultural backgrounds. A final limitation was the greater number of female participants than male participants. Given the higher prevalence of Parkinson's in the male population (Van Den Eeden et al., 2003) it may be pertinent to further examine the experiences of concepts such as physical self-perceptions and social support of males in group physical activity programs as there may be differences in the way males and females understand these experiences.

5.3 Future Directions

The findings from this research highlight the experiences of social comparison, social support, physical self-perceptions, and posttraumatic growth of those with Parkinson's involved in a group physical activity program. The use of humor as a mechanism for coping with anxiety has been examined in clinical populations such as cancer, however, it has not been examined extensively in those who have a degenerative disease such as Parkinson's or specifically within the context of group physical activity. Humor may be a mechanism by which people with Parkinson's normalize their progressing symptoms, mitigate stress associated with newly developed symptoms, and develop a shared connection with others. Being in a group physical activity environment may facilitate situations in which humor may be useful, for example, joking about taboo symptoms restricting certain physical activity tasks. Future research should examine how sharing humor about Parkinson’s in a group physical activity environment can aid in decreasing anxiety about the disease and increase a shared connection. The use of downward comparison affiliation to produce a positive self-image was a particularly interesting finding from this research given that previous research has consistently posited the negative effects of downward comparison affiliation. Future studies should track changes in social comparison over time as those with Parkinson’s begin and continue through a group physical activity program in order to determine how comparing to others Parkinson’s people’s physical activity abilities may lead to adaptive outcomes. Finally, the structure of a group physical activity environment for those with Parkinson’s may require special consideration of disease level and creating an environment in which people have the opportunity to both receive support and provide help to others. Future research should focus on shaping a group physical activity environment in which those with different levels of Parkinson’s may be physically active together in order to understand how being around others with different levels of ability may elicit comfort around helping others.

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APPENDICES

Appendix A Demographic Questionnaire

DEMOGRAPHIC INFORMATION

1. Age (years): ______________

2. Sex: ☐ Female ☐ Male

3. Ethnicity (check ***all*** that apply)
   - ☐ Caucasian
   - ☐ Asian
   - ☐ Hispanic
   - ☐ First Nations/Aboriginal
   - ☐ African
   - ☐ Other. Please specify: ____

4. What is your highest level of education?
   - ☐ Did not complete high school
   - ☐ High school diploma
   - ☐ Some post-secondary, but did not complete diploma or degree
   - ☐ College or technical diploma or certificate
   - ☐ University undergraduate degree
   - ☐ Post-graduate degree

5. What is your household income?
   - ☐ less than $20,000
   - ☐ $20,000 to $39,999
   - ☐ $40,000 to $59,999
   - ☐ $60,000 to $79,999
   - ☐ $80,000 to $99,999
   - ☐ $100,000 or more

6. Are you currently employed? ☐ Yes ☐ No

   If yes, please describe your occupation _________________________________

7. What is your marital status?
   - ☐ Single
   - ☐ Married or living with a life partner
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed

8. Weight (pounds) ___________________

9. Height (feet and inches) __________________

10. Have you ever had deep brain stimulation surgery to control symptoms associated with Parkinson's disease?

☐ Yes ☐ No

11. Please list your PD medication history below

Medication Name (Trade or generic name)	**Dose** (Specify units)

Appendix B Interview Guide

Introduction:

- Welcome and thank the participant
- My primary interest in this interview is to better understand your thoughts and feelings about your experiences of living with Parkinson's while participating in Rock Steady. Specifically, I am interested in your experience of physical challenges to participation and any psychological, social, or physical outcomes you may have experienced.
- Procedure: I am here to learn from you. I will ask certain questions, but I encourage you to include anything you feel is relevant. There are no right or wrong answers to these questions; I just want to better understand your perspective.
- I am going to be audio recording our discussion. The recordings and transcripts of the conversation are confidential, as outlined in the consent form. Information and quotations will be used in publications and presentations of this research, but your name and any other information that could identify you will be removed from such data.
- You have the right to choose not to answer any particular question or to end the interview at any point if you wish.
- Are there any questions before we begin?
- (Start the tape)

Questions:

Part 1: Background information and rapport building

1. When were you first diagnosed with Parkinson's disease?
    a. How did you feel when you found out?
    b. Did you experience any support from other people when you were first diagnosed?
        - In what ways were you supported?
        - Who were the people who provided you with that support?
            - medical personnel
            - Family (parents, siblings, spouses, children)
            - Friends
2. Have you experienced any changes related to Parkinson's since your diagnosis?
    a. Physical

   b. Psychological
   c. Social
   d. Other

3. How would you describe the support you get from other people ***outside of Rock Steady*** in helping you with Parkinson's?
   a. Do you feel you get the support you need?
   b. Are there any ways in which you need to or would like to be supported that you are not?
   c. Do any of the people who provide you with support outside of Rock Steady also have Parkinson's?
   d. Have you ever participated in a support group for Parkinson's? If so, what was that experience like for you?
   e. Are you still involved?
   f. How long have you been involved?

Part 2: Main research question

1. When did you first join Rock Steady?
   a. Why did you decide to join?
      - Did you have physical reasons for joining?
      - Emotional or psychological reasons?
      - Social reasons?
      - Other reasons?
   b. What were your perceptions of Rock Steady Boxing when you first decided to join?
      - Have those perceptions changed since you joined the group?
      - If so, how have they changed? What prompted those changes?

2. How do you feel about your ability to do the exercises in the Rock Steady program?
   a. How confident are you in carrying out the exercises?
      - Physically
      - Psychologically
      - How does this make you feel?

b. Do you experience challenges regarding doing the exercises in the Rock Steady program? If so, can you describe those challenges
    - How does facing those challenges make you feel?

c. Has your ability to do the Rock Steady training changed since you joined?
    - If so, please describe how.
    - How do you feel about these changes?

d. How do you feel about the level of class you are in?
    - Does it fit your level of ability?
    - Do you feel comfortable with the level you are in? Satisfied?
    - Do you interact with the other people in your classes? If so, please describe your relationships with the other people in your classes. What about your relationships with people in other levels of classes?

3. Can you describe the social environment at Rock Steady?
    a. Do you feel like you are accepted or belong with the other participants in Rock Steady? Please describe your experiences with the group.
    b. What are your relationships with the other participants in Rock Steady? Would you describe anyone as a friend? Please describe.
    c. Do you feel supported by the other participants in Rock Steady?
        - If so, how have they supported you?
        - Is the support you get from other participants in Rock Steady similar to the support you get from other people in your life? Please explain how it is similar/different.
        - Is it important for you to be supported by your teammates? Why is this support (not) important to you?
    d. Do you feel supported by the instructors/trainers at Rock Steady?

  - If so, please describe how they support you.
  - Is this support unique from support you receive from others in your life? Please explain
  - Is it important to you? Please explain

e. Has participating in Rock Steady had any effect on your relationships with other people in your life? If so, please explain.
  - Family ?
  - Friends?
  - Any other people within, or outside of Rock Steady?

4. Do you experience any challenges or difficulties with participation in Rock Steady? If yes, please explain
   a. Physical
      - Ability
      - symptoms
   b. Emotional
   c. Social
   d. Other

5. Do you think that the social relationships and support that you have experienced in Rock Steady has impacted you and your life in any way?
   a. If so, how has it impacted you?
      - Symptoms
      - Emotions
      - Relationships
      - Physical ability
      - Positively
      - Negatively
      - In your life outside of the program

6. Have you experienced any changes in your life as a result of being in Rock Steady Boxing?
    a. If so, can you describe how you've changed?
        - Symptoms
        - Emotions
        - Relationships
        - Physical ability
        - Positively
        - Negatively
        - In your life outside of the program
7. Do you have anything else you would like to add that has been important for you about your experience with Rock Steady?

Thank-You:

Thank-you very much for your participation in this project. We really appreciate your time and effort in completing the interviews for this study.

General Probes to be used:

- Can you tell me more about that?
- Could you give me an example of what you mean?
- Can you describe what you mean?
- Please elaborate on that idea.