An Investigation into the Feasibility and Benefit of Irish Set Dancing for People with Parkinson’s Disease

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University of Limerick

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Abstract

Title: An investigation into the feasibility and benefit of Irish set dancing for people with Parkinson’s disease
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Irish set dancing may be beneficial for people with Parkinson’s disease and encourage habitual exercise participation through the integration of dynamic balance activities, socialisation and musical enrichment. Currently, only one published study, which was carried out in a sample of Venetians with Parkinson’s disease, has investigated the feasibility of set dancing. Set dancing has a rich cultural heritage in Ireland and is a popular social and cultural activity in Ireland. Thus, research exploring the role of set dancing as an exercise activity in an Irish population is warranted. The aim of the project presented in this thesis was to investigate the feasibility and benefit of Irish set dancing for people with Parkinson’s disease in Ireland.

The findings of a systematic review and single-group feasibility study informed the methods of a multi-centered pilot randomised controlled trial (RCT). Ninety participants were randomised (n=45 per group) into a set dancing group and usual care control group. No adverse effects were reported. Attrition during the study was >40% in both groups and adherence to the intervention was 93.5%. Post-intervention, the dance group demonstrated greater improvements in quality of life compared to the control group. Motor function deteriorated in the control group. An exit questionnaire showed participants enjoyed the classes and would like to continue participation.

An educational resource to inform set dancing teachers about Parkinson’s disease was developed using information gathered from the research studies described in this thesis and the broader literature.

The results of this project provide new insights into the feasibility, safety and potential benefits of set dancing for those with Parkinson’s disease. These findings
along with the educational resource may guide future research, encourage
collaborations between health and dance disciplines and facilitate successful
implementation of community set dancing programmes for this population.
Declaration

I, the undersigned declare that this thesis is my own work and that the data presented is accurate. I declare that this thesis has not been submitted for any other award or degree at this or any other University.

Joanne Shanahan

_________________________  Date:   /   /
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List of Abbreviations

BDNF – Brain derived neurotropic factor

FITT principle - Frequency, Intensity, Time/ Duration and Type

RCT - Randomised controlled trial

Quasi-RCT - Quasi-randomised controlled trial

ICF - International Classification of Functioning, Disability and Health

UPDRS-3 - Unified Parkinson’s disease rating scale subsection-3

MDS-UPDRS-3 - Movement Disorders Society unified Parkinson’s disease rating scale subsection-3

PDQ-39 - Parkinson’s disease questionnaire-39

PDQ-SI - Parkinson’s disease questionnaire-39 summary index

PASE - Physical activity scale for the elderly

CDC - Centre for Disease Control and Prevention

COPD – Chronic Obstructive Pulmonary Disease


Glossary of Terms

**Irishness:** A sense of being Irish

**Céilí dancing:** A style of social dancing promoted by the Gaelic League. The steps involve kicking the heel off the buttocks while maintaining an externally rotated position of the legs and feet. The legs are also crossed in the midline. **Set dancing experience:** The process of engaging, feeling, enjoying and appreciating the multidimensional aspects of set dancing

**Céilí:** A social gathering where people come together and dance for 3-4 hours of the body and the heels are raised as high as possible from the ground so all steps are danced on the toes

**Set céilí:** A social gathering where people come together and dance sets for 3-4 hours

**Gent:** The male position of the dancing couple. The gent always stands to the left of the his dancing partner

**Lady:** The female position of the dancing couple. The lady is always positioned to the right of her dancing partner

**Little Christmas:** Two dancing couples swing in a group of four, turning in an clockwise direction

**Tops:** Two opposite dancing couples that stand facing each other in a set (Figure 2). Top couples are identified by the position of the musical accompaniment, i.e. one couple will have their back to the musicians and the other will be facing the musicians

**Side:** Two opposite facing couples that stand facing each other. Side couples are positioned to the right and left side of the top couples
List of Publications

The following is a list of publication and conference outputs related to this project. A list of manuscripts submitted for review for publication is also provided.

Peer-reviewed Journal Publications


Trial Register Publication


Conference Presentations: Platform, Poster, Workshop

trial”, Poster Presentation at Clinical Therapies Research Day, University of Limerick, Ireland.


Clifford, A.M. and **Shanahan, J.** "Practical recommendations for dancing for people with Parkinson's disease and the feasibility of Irish set dancing in Parkinson’s disease”, Platform Presentation at the International Health Conference on the Therapeutic Benefits of Set Dancing for Parkinson’s Disease (community engagement conference), Clare, Ireland.

**Shanahan, J. (2013) “Practical workshop of set dancing for people with Parkinson’s disease”, Workshop at the International Health Conference on the Therapeutic Benefits of Set Dancing for Parkinson’s Disease (community engagement conference), Clare Ireland.**


**Manuscripts Submitted for Review for Publication**


Chapter 1

Introduction to Research Project
1.0 Prologue

This chapter provides an introduction to the topic of this thesis; “Irish set dancing for people with Parkinson’s disease” and outlines the plan for the subsequent chapters of this thesis.

1.1 Epidemiology of Parkinson’s Disease

Parkinson’s disease is a neurodegenerative condition resulting primarily from the loss of dopamine producing cells in the substantia nigra nuclei of the basal ganglia (Pedrosa and Timmermann 2013). The cause of Parkinson’s disease remains largely unknown or idiopathic but some genetic and environmental factors such as pesticides and repeated traumatic loss of consciousness, have been identified as possible causes of this condition (Dick et al. 2007, Thomas and Beal 2007). There is also an association between lower levels of physical activity and Parkinson’s disease (Bellou et al. 2016).

Parkinson’s disease is the second most common neurodegenerative condition affecting approximately six million people worldwide (Baker and Graham 2004, Keus et al. 2014). In Europe Parkinson’s disease affects approximately 1.2 million Europeans (Keus et al. 2014) with a prevalence rate of 428 per 100,000 in individuals aged 60 to 69 years. The prevalence increases with age and it is estimated that 1601 per 100,000 adults, aged 70 to 79 years have Parkinson’s disease (Pringsheim et al. 2014). The majority of those with Parkinson’s disease are over 60 years of age but early onset of the condition can occur before the age of 40 in approximately 5% of those diagnosed (Keus et al. 2014). In Ireland it is estimated that 5691 people over 65 years have Parkinson’s disease (Lingdren et al. 2005). The incidence of Parkinson’s disease in females is 1.5 times lower than in males (Keus et al. 2014). This may be due to lifestyle differences as arguably, the occupation of more men exposes them to chemical toxins and injurious head traumas (Wooten et al. 2004).
With respect to economics, the annual cost of Parkinson’s disease is estimated to be 13.9 billion euro in Europe (Keus et al. 2014). The total expenditure related to Parkinson’s disease varies from country to country and may be related to population and prevalence differences. In 2004, the total economic burden of Parkinson’s disease was 47 million in Ireland (Lindgren et al. 2005). As the population ages, the economic cost is expected to rise in line with an increased prevalence of Parkinson’s disease (Keus et al. 2014).

1.2 Pathophysiology

Braack et al. (2004) described Parkinson’s disease as a progressive multisystem pathology involving six stages (Figure 1.1). This degenerative process advances in a predictable pattern in specific brain regions. The mechanisms underlying the degeneration associated with the pathology of Parkinson’s disease are not fully understood. However, a primary feature is Lewy body formation which results from an aggregated form of alpha-synuclein protein. Mitochondrial dysfunction, oxidative stress and neuroinflammation may also be involved in the pathology of Parkinson’s disease (Thomas and Beal 2007, Zigmond and Smeyne 2014, Akbar et al. 2016).

According to Braack et al. (2004), stage one and two of the pathology of Parkinson’s disease involve degeneration in the medulla oblongata and pons. Degeneration in these structures worsens with disease progression. This may impair acetylcholine, noradrenaline and serotonin transmission and contribute to the development of some non-motor symptoms such as autonomic and sleep dysfunction and mood symptoms (Grinberg et al. 2010, Sung and Nicholas 2013).

Motor symptoms, which result from dopamine depletion in the nigrostriatal pathway, occur in stage three (Braack et al. 2004). Nigrostriatal pathology is the key pathological feature of Parkinson’s disease and subsequently impairs function in several brain regions including the supplementary motor cortex, primary motor cortex and pedunculopontine nucleus (Morris and Iansek 1996, Jankovic 2008, Bonnet et al. 2012). Initially, only the dorsolateral posterior putamen nucleus of the stratum is affected (Pavese and Brooks 2013). However, over time degeneration of
the substantia nigra pars compacts becomes more extensive and spreads to the ventral tegmental area (Braack et al. 2004, Pavese and Brooks 2013). This leads to a widespread dysfunction of striatal nuclci including the caudate and nucleus accumbens (Pavese and Brooks 2013) and may contribute to the development of cognitive impairment, depression and apathy (Blonder and Slevin 2011, Hanganu et al. 2014, Mavridis 2014, Vriend et al. 2014). The final stages of Parkinson’s disease are marked by severe degeneration in areas of the neocortex including the premotor area (Braak et al. 2004).

Figure 1.1 Multisystem Pathology of Parkinson’s Disease
1.3 Clinical Features

Parkinson’s disease is characterised by motor and non-motor symptoms (Keus et al. 2014). Resting tremor, rigidity and bradykinesia are the main motor symptoms associated with Parkinson’s disease (Morris 2000, Petzinger et al. 2013). Approximately 70% of those diagnosed have a resting tremor. This figure increases with disease progression (Keus et al. 2014). Rigidity and bradykinesia affect over 76% of those with Parkinson’s disease (Keus et al. 2014). Postural instability and gait dysfunction such as freezing of gait are seen in a large proportion of patients and become more evident with disease progression (Nutt et al. 2011, Kim et al. 2013). Ambulatory activity levels also decline over time in those with Parkinson’s disease (Cavanaugh et al. 2015). Additionally, freezing of gait is associated with a more rapid deterioration in postural stability (Vervoort et al. 2016) and reduced gait speed and/ or freezing of gait may lead to functional decline (Tan et al. 2012), social isolation (Chiong-Rivero et al. 2011) and an increased risk of falls (Robinson et al. 2005). Importantly, a history of falls is a risk factor for recurrent falls as well as a longer disease duration and cognitive impairment (Allen et al. 2013). Thus, falls can result in injury, fear of falling, reduced activity levels (Rudzińska et al. 2013) and quality of life (Gazibara et al. 2015). Moreover, participation in family and social activities declines (Chiong-Rivero et al. 2011) and strategies that promote social interaction are needed. Physical inactivity can also lead to secondary consequences of inactivity such as cardiovascular disease or osteoporosis and negatively affect motor and non-motor aspects of Parkinson’s disease (Speelman et al. 2011).

Many people with Parkinson’s disease experience non-motor symptoms such as mood and psychiatric symptoms, cognitive impairment, sleep abnormalities and autonomic dysfunction (Jankovic 2008, Bonnet et al. 2012). The incidence of non-motor symptoms varies. Depression affects approximately 27.6% in the early stages of the disease (Bonnet et al. 2012). The prevalence of apathy is 30-40% and sleep disorders affect 66-99% of patients (Bonnet et al. 2012). Those with longer disease duration can have a greater severity of non-motor symptoms although they can arise at any stage during the disease (Keus et al. 2014). Non-motor symptoms can have significant impact on quality of life (Schrag et al. 2000b, Skorvanek et al. 2015) and
socialisation (Wressle et al. 2007, Soleimani et al. 2014) and can go untreated due to insufficient subjective reporting and assessment (Bonnet et al. 2012).

1.4 Management

A multidisciplinary team approach, combining pharmacological and non-pharmacological treatment strategies are needed to effectively manage motor and non-motor symptoms (Iansek and Morris 2013a, Pedrosa and Timmermann 2013, Keus et al. 2014). Neurosurgery may also be suitable for some people with Parkinson’s disease and has been shown to improve motor complications associated with long-term levodopa use, severe tremor and (Pedrosa and Timmermann 2013) gait stability (Johnsen et al. 2009). Surgical procedures are sometimes associated with side effects such as psychiatric and cognitive problems (Pedrosa and Timmermann 2013). The patients, together with the multidisciplinary team should be involved in the decision-making process for surgery (Pedrosa and Timmermann 2013).

Pharmacological therapies including levodopa and dopamine agonists are used to treat motor symptoms associated with Parkinson’s disease (Pedrosa and Timmermann 2013, Kriebel-Gasparro 2016). They are most effective in treating bradykinesia, tremor and rigidity (Pedrosa and Timmermann 2013, Tierney and Lozano 2013). However, postural instability can have a limited response to pharmacological therapies and some therapies may worsen aspects of postural (Bronte-Stewart et al. 2002, Rocchi et al. 2002) and can exacerbate some non-motor symptoms such as cognitive impairment (Wishart and Macphee 2011). Additionally, long-term use of levodopa, is associated with motor fluctuations and dyskinesia in approximately 50% of patient taking this medication (Kriebel-Gasparro 2016). This results in the re-emergence of gait difficulties and an increased risk of falls (Gray and Hildebrand 2000, Robinson et al. 2005, Kriebel-Gasparro 2016). Motor fluctuations may also cause early morning stiffness which can reduce quality of life and increase caregiver burden (Onozawa et al. 2016). Therefore, non-pharmacological therapies are needed (Keus et al. 2014).

Despite numerous studies illustrating the potential benefits of exercise, long term adherence to physical activity programmes remains problematic and people with Parkinson’s disease are approximately one third less active than controls (Earhart
Furthermore, findings suggest that 64% of people with Parkinson’s disease lead sedentary lifestyles and participate in less than 150 minutes of exercise per week (Hirsch et al. 2011). This may lead to further disability, muscle wasting and postural instability (Speelman et al. 2011, David et al. 2012). Gait disability (van Nimwegen et al. 2013), fear of falling (Ellis et al. 2013), fatigue (Wressle et al. 2007), and slowness of lower limb movement (Lana et al. 2016) may contribute to reduced physical activity levels. Poor expectation from exercise, lack of motivation (Ellis et al. 2013) and environmental barriers (Nilsson et al. 2015) have also been identified as potential barriers to exercise in people with Parkinson’s disease. Additionally, research dissemination and translation to combat inadequate community facilities and educate community personnel can be lacking (Hirsch 2009, Jacobs et al. 2012, Neta et al. 2015).

Therefore, there is a growing need to develop more attractive exercise programmes that (1) help to overcome barriers to exercise and (2) encourage people with Parkinson’s disease to engage in regular physical activity (Hirsch 2009, Hirsch et al. 2011).

### 1.5 Dance

Dancing may be one alternate form of exercise for people with Parkinson’s disease. Dancing is a type of physical activity that encompasses fundamental rehabilitation components for people with Parkinson’s disease. These components include cueing strategies, balance and endurance training and focusing attention on movement strategies. Dancing is also a social activity and may help improve physical activity levels and quality of life through social interaction, relaxation and enjoyment (Thomas 2001, Keogh et al. 2009, Centre for Policy on and Ageing 2011, Gallagher 2012, Takahashi et al. 2016). To date, much of the dance literature in Parkinson’s disease has focused on Tango (Hackney and Earhart 2009a, Foster et al. 2013) and different forms of modern dance (Marchant et al. 2010, Heiberger et al. 2011). These studies have reported improvements in balance (Hackney et al. 2007b), mobility (Hackney and Earhart 2009a), motor impairment (Duncan and Earhart 2012) and quality of life (Hackney et al. 2009b, Heiberger et al. 2011). In the elderly
population, studies have reported that dance was superior to Tai Chi Chun and a falls prevention programme for improving cognitive flexibility (Coubard et al. 2011). Regular set dancing participation in older adults is also associated with better endurance, balance and quality of life (Shanahan et al. 2016a), however, limited research has examined the benefit of set dancing or other cultural dance forms for people with Parkinson’s disease. Additionally, the methodological quality of the studies that examined the benefit of dance for people with Parkinson’s disease has not been appraised. There is also a lack of information about the most appropriate frequency, intensity, duration and type of dance (FITT principle) for people with Parkinson’s disease. Therefore, a more detailed synthesis of the current literature on dance for people with Parkinson’s disease is described in Chapter 3.

1.6 Irish Set Dancing

This section introduces the potential benefits of set dancing for people with Parkinson’s disease and discusses current research in this area. The knowledge gained in this section facilitates an understanding of this topic and justifies the need for an in-depth discussion of the potential benefits of set dancing from a combined perspective of arts and health. Therefore, Chapter 2 will provide a comprehensive discussion of this interdisciplinary topic.

Irish set dancing may be a beneficial form of dance for people with Parkinson’s disease. Irish set dancing is a social dance type that has a rich history embedded in Irish cultural (Lynch 1989, O’Connor 2013). For generations, Irish set dancing has been viewed as a relaxing, enjoyable and motivating form of exercise that fosters and builds family and community connectivity (Foley 2011, O’Connor 2013). For people with Parkinson’s disease, set dancing may have a number of potential benefits. Set dancing steps and movements may improve balance by providing repetitive weight-shifting practice in an antero-posterior and medio-lateral direction. This is a fundamental component of postural stability and can be problematic for some people with Parkinson’s disease (Vervoort et al. 2013).
Physical decline and problems performing activities of daily living have been shown to negatively impact upon quality of life (Schrag et al. 2000b, Kleiner-Fisman et al. 2010). Several functional tasks including repetitive movement initiation and termination, forwards and backwards movements, turning and reaching are routinely performed when set dancing (Murphy 2000). The stepping strategies used in the set dancing steps are also comparable with the phases of gait (heel strike, stance and swing) (Murphy 2000, Volpe et al. 2013) and may improve mobility (Herman et al. 2007, Cheng et al. 2013). This could have positive implications on participation in activities of daily living and quality of life (Tan et al. 2012, Soh et al. 2013). The external cue of Irish music in set dancing may improve movement generation which can help to make movements bigger and faster (Raglio 2015a).

In terms of participation, set dancing may overcome perceived barriers to exercise (Ellis et al. 2013) and encourage long-term participation and adherence as it incorporates socialisation and spousal participation (Foley 2011, O’Connor 2013). These have been previously identified as key elements needed to motivate adherence with physical activity in people with Parkinson’s disease (Ravenek and Schneider 2009, Crizzle and Newhouse 2012). Set dancing is also a social activity and this may help to combat social isolation, build supportive networks to encourage self-management and encourage participation (Hirsch et al. 2011, Chaudhury et al. 2016). Participation in partnered dance styles is also associated with perceived physical, cognitive, social and emotional benefits (Lakes et al. 2016) and may improve satisfaction and long-term participation (Thomas 2001). Figure 1.2 summarises the potential benefits of set dancing for people with Parkinson’s disease.
Currently, there is only one published study that has investigated the effect of set dancing for people with Parkinson’s disease (Volpe et al. 2013). This feasibility study was carried out in a sample of Venetians with Parkinson’s disease and found improvements in quality of life, balance, motor function and mobility following the set dancing intervention. However, further research is needed to confirm the findings of this feasibility study. Additionally, no study has determined if set dancing is feasible in Ireland for people with Parkinson’s disease. Research in the Irish population with Parkinson’s disease is particularly important because set dancing is a popular activity and it is plausible that some people may have ceased participation due to a lack of Parkinson’s specific classes. Arguably, this may have negatively affected social participation and activity levels. In Ireland, set dancing is mostly recognised as a social, creative and cultural art form and little consideration is given to the health benefits of set dancing (Foley et al. 2011, O’Connor 2013). Thus, it is important to consider the combined perspectives of arts and health disciplines when designing and implementing set dancing programmes for people with Parkinson’s disease in Ireland.
Hence, the aims of the research project presented in this thesis were to:

- examine and critically appraise existing literature that investigated the benefit of dance for people with Parkinson’s disease
- implement and evaluate the feasibility of a community set dancing programme for people with Parkinson’s disease
- investigate the feasibility of a RCT study design and compare the benefits of set dancing to usual care for people with Parkinson’s disease
- disseminate the findings of this research project by developing an educational resource to guide community set dancing teachers teaching set dancing to people with Parkinson’s disease

Figure 1.3 diagrammatically summarises the research process involved in achieving the aims of this thesis and illustrates the interdependent connections between each stage of this research project.
To address the aims of this research project, a number of research studies were completed. These studies are presented in the following chapters:

- **Chapter 2:** “Creativity in Arts and Health: Emergence of Irish Set Dancing for People with Parkinson’s Disease” explores the potential health benefits of the set dancing with reference to structural, movement, musical and social characteristics of set dancing. The historical basis of set dancing is also contextualised within the area of arts and health. This chapter provides important knowledge to inform the development of the set dancing programme evaluated in the feasibility study and pilot RCT.

- **Chapter 3:** “Dance for People with Parkinson’s Disease: What is the Evidence Telling Us?”, presents a systematic review that was performed to evaluate and synthesize the literature on dance programmes for people with Parkinson’s disease. This review identified methodological limitations and gaps in the current literature. These results informed the methodology of the research projects undertaken as part of this investigation. The results also informed the educational resource (Appendix A) that was developed as part of this project. Valuable clinical information regarding potential benefits of dance and an appropriate dosage for people with Parkinson’s disease is also discussed.

- **Chapter 4:** “Is Irish Set Dancing Feasible for People with Parkinson’s Disease in Ireland?” describes a feasibility study. This study is novel in that it investigated the feasibility of a community set dancing intervention in Ireland. The findings provided information on treatment dosage, safety aspects of set dancing and suitability of outcome measures. The data collected informed the methodology of the multi-centered pilot RCT and the educational resource presented in Appendix A.

- **Chapter 5:** “Dance for Parkinson’s: A Randomised Controlled Pilot Trial of Irish Set Dancing Compared to Usual Care” consolidates the information presented thus far in the thesis and presents a multi-centered pilot RCT. This
pilot trial examined the feasibility of a RCT study design and explored the benefits of the set dancing intervention compared to usual care. The findings of this study provided important information to inform the content of an educational resource for set dancing teachers (Appendix A).

- Chapter 6 and 7 describe the methods used to develop an educational resource for set dancing teachers. The aim of the educational resource is to disseminate the findings of this research project and guide community set dancing teachers teaching set dancing to people with Parkinson’s disease. Chapter 6 “Protocol for Development and Completion of Educational Resource Booklet” details a four phase methodological procedure used to develop the educational resource. Chapter 7 “Irish Set Dancing Classes for People with Parkinson’s Disease: The Needs of Participants and Dance Teachers” presents a cohesive exploration of the methods and results used during Phase 1 of the development of the educational resource (Appendix A). Specifically, the needs of people with Parkinson’s disease from Irish set dancing classes and the educational guidance sought by community set dancing teachers to facilitate them to teach set dancing to people with Parkinson’s disease were explored.

- Chapter 8 provides a consolidated discussion of the key findings of this project and contextualises them within the broader arts and health literature. The national and international impact of this project for people with Parkinson’s disease, clinical practice and research is also discussed.
Chapter 2

Creativity in Arts and Health: Emergence of Irish Set Dancing for People with Parkinson’s Disease

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

- Narrative review
- Systematic review
- Feasibility study
- Pilot RCT
- Dissemination
2.0 Prologue

This chapter builds on the information provided in Chapter 1 and describes the role of set dancing as an arts and health initiative for people with Parkinson's disease. Considering the combined perspectives of the arts and health disciplines, this chapter examines the historical, structural and movement characteristics of set dancing and explores their relationship to therapeutic dance and the potential health benefits for people with Parkinson's disease. The information provided in this chapter substantiates the rationale for this investigation into the feasibility and benefit of set dancing for people with Parkinson's disease and provides comprehensive background knowledge to inform the subsequent chapters of this thesis. The article based on this review was submitted for review for publication to the *Journal of Creative Behaviour* (14 March 2016).

2.1 Introduction

The connections between Irish set dancing, health and wellbeing are not well explored in the published literature. This is particularly the case in movement disorders such as Parkinson’s disease (Shanahan *et al.* 2015b). Recently there has been a resurgence in interest in dancing and other forms of physical activity for older adults, those seeking greater social connections and people with neurological conditions such as Parkinson’s disease (Pitkala *et al.* 2011, McNeely *et al.* 2015a). Therapeutic dancing for people with Parkinson’s disease is argued to provide sustained aerobic exercise, particularly when it incorporates carefully selected music with a rhythmical beat and strategies to enhance performance and adherence (Keogh *et al.* 2009, Crizzle and Newhouse 2012, Beevers *et al.* 2015, Dhami *et al.* 2015). The combination of physical and cognitive elements in dance may activate a larger number of brain regions and have additional neuroplastisic effects compared to physical or cognitive activities alone (Dhami *et al.* 2015). Community-based dancing classes that are accessible can also help to build social networks, improve general wellbeing, as well as enable people to enjoy the beneficial effects of exercise (Cohen *et al.* 2006, Skinner 2013, McGill *et al.* 2014, Roberson and Pelclova 2014).
Irish set dancing is a social and creative form of cultural art. Irish set dancing has positive effects on balance and health related quality of life (Volpe et al. 2013, Shanahan et al. 2015a). Set dancing is commensurate with other dance genres including Tango and Waltz and Foxtrot and involves transitions between static and dynamic postures, turning and the support of a dance partner (Hackney and Earhart 2009a, Shanahan et al. 2015a). However, the addition of the group context of set dancing may offer different postural challenges, variability in movement sequences and social interactions. The rhythmic sequence of set dancing steps involves a well-defined pattern similar to gait. This may improve walking tasks in people with Parkinson’s disease (Volpe et al. 2013). Learning and memorising set dancing steps and movements provides cognitive exercise and may help preserve and or improve cognitive function (Dhami et al. 2015). Furthermore, the cultural social context of set dancing may stimulate enjoyment and satisfaction and motivate long-term participation in people with Parkinson’s disease and older adults (Allen and Morey 2010, Cuypers et al. 2012, de Dreu et al. 2015).

In Ireland, set dancing has formed a unique part of community, family and social identity for centuries, despite a challenging period in the 20th century when embodied representations of “Irishness” were contested (Phelan 2014). Today, set dancing is one of the most popular national dance forms and is practiced worldwide (O’Connor 2013). Despite the popularity and benefits of set dancing, it appears few attempts have been made to integrate this art form into community health promotion programs. This may be partially due to a lack of knowledge, training or education (Arts Council 2010). For example, set dance teachers may be unaware of the health benefits of set dancing or modifications that may be needed to classes, steps or music in order to suit older adults, people with Parkinson’s disease or individuals with mobility limitations and co-morbidities. Some health professionals may be similarly under-trained with respect to the beneficial effects of cultural and movement characteristics embodied in the “set dancing experience” or in other art and alternative forms of therapy (Russell 2007, Ventola 2010, Sapouna and Pamer 2012). As dance is a form of art and exercise, an appreciation of both the arts and health perspectives may enable people to better engage, understand and experience the enjoyable rewards of set dancing participation (Arts Council 2010). Many effective
public health initiatives are characterised by (1) inter-professional and cross sector team collaborations and (2) an appreciation for the expertise, contributions and practices of each discipline (Russell 2007, Sapouna and Pamer 2012, Stranges et al. 2015). Arguably there is a need to bridge the gap between the arts and health professions for the successful implementation of community Irish set dancing programmes for people with Parkinson’s disease.

The aim of this narrative review is to explore potential bridges between dancing and healthcare communities, as they relate to Irish set dancing. Objectively, three pedagogical themes will be discussed. Firstly, the historical elements of set dancing will be explored and followed by an analysis of the structural and movement characteristics of this dance genre. The potential health benefits of set dancing will then be evaluated and links will be drawn between this art form, health and rehabilitation. Significantly, this approach amalgamates the therapeutic and creative aspects of Irish set dancing and illustrates it’s potential effect on physical and emotional health, as well as psychological wellbeing. This novel approach may be transferable to other dance genres and help researchers and arts and health professionals to collaborate, enhance their knowledge and develop creativity-based programmes for therapeutic community and rehabilitation dance classes.

2.2 Historical Elements of Set Dance and their Link to Health

Irish set dancing originated from the French quadrilles, a genre of dance popular in the late 18th and 19th century (Foley 2011). In the early 19th century, the quadrilles came to Ireland via esteemed dance teachers called “dance masters” from England, Scotland and France. These dance masters taught the French quadrilles at classes across the country. Gradually the French quadrilles were adapted to complement Irish music and social culture (Murphy 2009, Foley 2011) and they became a greater symbolic representation of Irish cultural and social experiences. During the 19th century Irish set dancing became a major source of entertainment for the general community, particularly in rural areas with dances held in homes and at the crossroads (O’Connor 2013). As popularity grew, many rural and urban areas enhanced community identity by choreographing their own local set with distinctive
creative elements and performance styles (Murphy 1995, Murphy 2009). This shows the fundamental place that set dancing can have, as an everyday exercise and a vehicle for community connectedness in people with Parkinson’s disease (Foley 2011). Set dancing was also a social event (O’Connor 2013). Communication methods were unsophisticated during the 19th century and the continued spread of set dancing even that long ago suggests that motivational factors accompanied action-observation between younger and older generations. This is important for both arts professionals such as dance teachers and health professionals such as physiotherapists as long term adherence and compliance with exercise can be problematic (Linke et al. 2011), especially in those with Parkinson’s disease and the elderly (Picorelli et al. 2014, Wallén et al. 2015).

In 1893, an organisation called the Gaelic League was set up to promote Irish culture including Irish language, music, song and dance (Brennan 1994). As set dancing originated from the French quadrilles, the Gaelic League classified it as a “foreign” dance genre and banned its practice nationally during the 1930’s. This resulted in a short term decline of set dancing participation. The Public Dance Hall Act 1935 led to further decline in set dancing as dances in homes and at crossroads were illegalised (O’Connor 2013). As a result, dances could only be held in dance halls. The term ceili, borrowed from the Scottish dance tradition, was used to describe the dance events held in dance halls (Brennan 1994). Subsequently, Céili dancing, a form of Irish dancing perceived to be more authentically Irish, was promoted in an effort to foster a truly Irish culture (Brennan 1994). Notably, céili (plural of this is céilithe) conducted under the auspices of the Gaelic League promoted Céili dancing which was collected and published by the Gaelic League. Many dances, including sets dances, which had been in the public domain in rural communities for years were excluded. The requirement to speak Irish at Gaelic League events, potentially excluded those who may have had a large dance repertoire but limited knowledge of the Irish language. At that time, this may have negatively affected community cohesion and a sense of belonging.

By the 1970’s, the radical deterioration of the set dancing tradition initiated fears of extinction of this dance genre (Phelan 2014). Several set dance masters began to
revive the set dance tradition (Breathnach 1983). These masters travelled around Ireland gathering and learning sets to disseminate at classes and in books. Famous dance masters include Connie Ryan and Pat Murphy (Foley 2011). A major part of this revival process was the introduction of the set céili, a place where an authentic sociable, energetic, friendly and free atmosphere domineered (O’Connor 2013). Ironically, set céili became more popular than ceili organised by the Gaelic League, indicating the positive emotional and cultural experiences afforded by set dancing (Ratner 2000). Set ceili permitted a multi-lingual dance environment, creating a sense of belonging and pioneering foundations for a cohesive set dance community with international participation. This may target social isolation often experienced by people with Parkinson’s disease (Soleimani et al. 2014). Today, set dancing is a popular form of dance in Ireland (Devlin 2014) with céilithe, workshops, classes and set dancing weekends organised all year round (Murphy 1995, Foley 2011). The popularity of set dancing internationally is also evident with events such as Fleadh Espana and Fleadh Portugal being organised annually (Foley 2011), yet another indication of the global spread of this dance form. This illustrates its potential role as a creative exercise in arts and health programmes worldwide.

2.3 Structural, Movement and Therapeutic Characteristics of Set Dancing

2.3.1 Structure of Set Dancing

A set generally consists of eight dancers arranged into four couples (sets with only two couples are called "half sets"). Couples are positioned to form a square with all dancers facing inwards (Figure 2.1). This formation constitutes the basic starting position for all set dances. Traditionally each dancing couple was composed of a gent (male partner) and lady (female partner). Notably, World War 1 and resulting emigration of men led to an acceptable culture of ladies dancing the gent's role in this couple (Nicholson 2007). In set dancing partnered and solo movements are interspersed in all dances. Arguably, this may provide support (de Dreu et al. 2015) and help improve balance self-efficacy in individuals with Parkinson’s disease (Mak and Pang 2008).
As identified by Allen and Morley (Allen and Morey 2010), peer support and socialisation are key elements needed to motivate exercise participation and should be recognised when implementing creative arts and health programmes for those with movement disorders such as Parkinson’s disease. The themes of community and social networks are strong creative features in set dancing choreography and may ameliorate social isolation often experienced by older adults and those with chronic conditions such as Parkinson’s disease (Holley 2007, Cornwell and Waite 2009). In this context community is defined as a dancing relationship that creates communal interests (O’Connor 2013). A closer exploration of the basic set structure exposes the existence of three distinct communities. The first and largest social network exists between all eight dancers in a set (Figure 2.2a) (Foley 2011). This configuration may be viewed as a "fluid" community with dancers or community members continually moving and greeting to cohesively perform movement sequences. A second support network is evident between two opposite facing couples (Figure 2.2b). These opposite facing couples constitute a smaller community network, aiming to successfully complete movements such as the ladies’ chain, which will be described in section 2.3.2. The sense of shared values and identity is further enhanced through the application of positional labels where two facing couples are called either “tops” or "sides", depending on their position. The final and most immediate community exists between the dancers in every couple (Figure 2.2c). This concept this portrayed in movements such as the swing where the
sensation of touch, created through the waltz hold, enables dancers to support and work together to complete this shared movement. The starting position of every couple also represents their "home", a place predominantly associated with support, identify and common goals. The idea of social interaction and networking may be further enhanced at set céilí as 10-20 sets perform together with “craic", fun and music intertwined. The presence of community and collaboration in set dance may create a sense of belonging, identity and reward (Kavanagh et al. 2008). For some people with Parkinson’s disease, this may alleviate the negative psychological consequences often associated with changing or loss of family and social roles (Chiong-Rivero et al. 2011). The cultural context of set dance may enhance the “real life” connections, as memories and nostalgia foster social networking and cohesion (Jain and Brown 2001).

Figure 2.2a First community within a Set

“O” shape=lady, “X” shape=gent

Figure 2.2b Second Community within a Set

“O” shape=lady, “X” shape=gent
Irish set dancing incorporates movement sequences into dances called sets. There are hundreds of sets in existence today with many named after founding geographical areas, creating a sense of identity and belonging (Murphy 2000). All sets have distinctive movement sequences arranged into a number of parts called figures. The number of figures in each set varies greatly but the majority contain between four and six. Each figure is danced to a particular type of traditional Irish music tune for example reel, hornpipe, jig, polka or slide (Murphy 2000) (please refer to Vallely 2011 (Vallely 2011) for a further description of these tunes). All sets contain varying quantities of these musical tunes, though patterns of preference are evident in some. For example, Clare sets, from the west of Ireland, usually consist of reel figures, while polkas and slides are the main feature in the south west region of Ireland (Murphy 2000). Consequently, set dancers in different regions of Ireland tend to have more experience of and a preference for certain dances. This may also be the case for people with Parkinson’s disease and arts and health professionals may need to consider the importance of local traditions in order to maximise participation and enjoyment in set dancing programmes.
2.3.2 Set Dancing Movements and their Therapeutic Potential

Movement sequences in set dancing involve group formations of shapes either through straight lines, multidirectional movements or rotational and stationary dancing (Shanahan et al. 2015a). Common movement sequences include circle, swing and ladies’ chain. Figure 2.3a and 2.3b illustrate a selection of these movements. A circle involves all dancers holding hands in the air and dancing an inward and outward stepping strategy for eight bars of the music. In a swing, each couple holds their partner in a waltz position and uses a particular pivoting stepping strategy, with the right leg in front, to turn in a clockwise direction (Murphy 2009). A ladies’ chain is a courtesy movement that involves ladies dancing around the opposite gentleman and returning back to meet their partner (Murphy 2000).

**Figure 2.3a Circle Movement**

![Circle Movement Diagram](image)

“O” shape=lady, “X” shape=gent

**Figure 2.3b Top ladies’ Chain**

![Top ladies’ Chain Diagram](image)

“O” shape=lady, “X” shape=gent
With respect to health benefits, set movement sequences and group choreography provide practice turning, moving forwards and backwards and translating between static and dynamic postures (Murphy 2009). Movements such as these can sometimes be problematic for people with balance impairments arising from Parkinson’s disease and other neurological conditions (Morris 2000, Chou and Lee 2013, Fritz et al. 2013, Rochester et al. 2013). Set dancing may provide a safe opportunity to practice these skills and thus may improve balance and help to reduce falls risk (Volpe et al. 2013, de Dreu et al. 2015). People with postural instability may also have difficulty with obstacle negation in everyday environments (Lamont et al. 2012, Stegemöller et al. 2012). The group formation of set dancing might improve this task as dancers must carefully negotiate around other dancers with continuous directional change. The group aspect of set dancing as well as the partnering involved may provide a visual cue to facilitate motor output during successive movement patterns and regulate step length. This may facilitate participation by minimising the influence of movement symptoms such as festination, bradykinesia and potentially freezing of gait in dance performance.

2.3.3 The Benefits of Set Dancing Steps

Creech and colleagues (Creech et al. 2013) found that active music making in later life was associated with enjoyment, personal development and empowerment. Set dancing involves an element of active “music making” through rhythmic dance performance. The three most popular steps in set dancing are the reel, polka and hornpipe (Murphy 2009). While the style of these steps can vary in different locations, the basic rhythmic pattern remains constant and enhances the rhythmical music cues which can facilitate movement in those with Parkinson’s disease (Rocha et al. 2014). When teaching set dancing it may be preferable to teach local dance styles as familiarity may aid motor learning (Mattar and Gribble 2005, Smith et al. 2005, Buccino 2014). Pleasant memories of previous set dancing experiences may also aid learning by facilitating a positive emotional state (Buchanan 2007) and thus, enhance motivation for task engagement (Petzinger et al. 2013). Each step has a specific movement pattern and requires precise foot placement. The reel step is very similar to gait. It involves forward acceleration with stance and swing phases.
(Murphy 2009) and may improve mobility in people with Parkinson’s disease (Volpe et al. 2013). The hornpipe step is the same as the reel but is danced to a slower music tempo; an important consideration for individuals with reduced balance, mobility or endurance and impaired active braking of the centre of gravity during gait (Chastan et al. 2009). The polka step requires repetitive weight-shifting and single leg stance in a medio-lateral direction (Murphy 2009). Weight-shifting and single leg stance tasks are commonly integrated into balance rehabilitation exercises and suggest polka dancing may positively affect functional ability and risk of falls in those with Parkinson’s disease and older adults (Ashburn et al. 2007, Cofré Lizama et al. 2014, Kamińska et al. 2015, Morris et al. 2015). This step is more challenging and should only be practiced when the person has sufficient balance to enable safe performance.

2.3.4 Therapeutic Set Dancing: Additional Health Implications

As a form of dance, Irish set dancing, with variable steps, sets and options for musical accompaniment, may offer a more interesting and artistic exercise environment compared with routine exercise prescription (Murphy 2000, Hackney et al. 2007a, Hackney et al. 2007b, Belardinelli et al. 2008, Keogh et al. 2009, McGill et al. 2014, Fernández-Argüelles et al. 2015). The long-term popularity of set dancing suggests that some older people or those diagnosed with Parkinson’s disease may have previously engaged in set dancing yet stopped due to reduced mobility, fear of falling or fatigue (Wressle et al. 2007, Duncan and Earhart 2011). Reduced ability to engage in habitual activity can negatively affect quality of life (Thomas 2001). Progressive reductions in movement and physical activity can have negative effects on mobility, independence and quality of life, especially in and people with chronic conditions such as Parkinson’s disease and older adults (King 2001, Rodrigues et al. 2006, Paterson and Warburton 2010, Speelman et al. 2011). An increase in sedentary behaviour can also predispose people to muscle weakness, balance difficulties and falls (Dionyssiotis 2012, Rochester et al. 2013). As the number of older adults is increasing, it is estimated there will be a concurrent rise in many chronic conditions including Parkinson’s disease (Keus et al. 2014, World Health Organisation 2011). This has created a need for physical activity that promotes a sense of achievement and benefit to sustain exercise participation and

Literature is emerging on the therapeutic potentials of community exercise activities including dance (McNeely et al. 2015a), yoga (Sharma et al. 2015) and boxing (Combs et al. 2011). Exercise classes available in the community may encourage habitual exercise participation through behavioural change and simple integration in everyday life (Andersen et al. 1999, Opdenacker et al. 2008). Involving people in community activities, commonly practiced in society, may be very rewarding for people with Parkinson’s disease or older adults and help them to join social networks (Jain and Brown 2001, Cohen et al. 2006, Cornwell and Waite 2009, Soleimani et al. 2014). Moreover, set dancing gives spouses, family members and carers an opportunity to take part (Shanahan et al. 2015a). This may strengthen relationships and help improve quality of life and burden, often experienced by caregivers (Christofoletti et al. 2011, Carod-Artal et al. 2013, Rodríguez-Violante et al. 2015); although further investigation is needed to confirm this. Social dancing may also increase activation of the mirror systems and aid learning through active-observation of other dancers (Dhami et al. 2015). Action observation has also been found to improve freezing of gait in people with Parkinson’s disease (Pelosin et al. 2010) and thus, set dancing could positively impact on this motor symptom.

2.3.5 Potential Neural Effects of Set Dancing

Exercise-induced neuroplasticity may be one of the physiological mechanisms contributing to the benefits of set dancing for those with Parkinson’s disease (Petzinger et al. 2013). For instance, neurogenesis in the hippocampus may improve learning and memory tasks while angiogenesis in the motor cortex, cerebellum and hippocampus may improve vascular brain health as well as learning, memory, balance and other motor skills (Dhami et al. 2015). Animal studies suggest aerobic exercise can modulate dopamine transmission in corticostriatal circuits and up-regulate markers or neurogenesis including BDNF (Zigmond and Smeyne 2014, Petzinger et al. 2015). Physical activity in elderly also induces an adaptive increase
in antioxidant enzyme activity regulating the oxidative stress (Fraile-Bermúdez et al. 2015). Furthermore, exercise commensurate with the combination of goal-directed learning and aerobic exercise in set dancing is suggested to enhance neuroprotective and neurorestorative mechanisms (Petzinger et al. 2013, Petzinger et al. 2015) and may have additional benefits for older adults and people with Parkinson's disease. While we cannot generalise directly between the exercise literature and dance, functional magnetic resonance imaging studies in humans have shown increased putamen activation in response to cued Tango movements (Brown et al. 2006) and increased connectivity between the basal ganglia and premotor cortex after an improvisational dance programme (Batson et al. 2014). This suggests dance may have positive implications for neural functioning in those with Parkinson’s disease. Therefore, it is possible that the enriched physical, sensory and social environment associated with set dance might enhance these neural processes aforementioned, along with endurance, balance and mood in those with Parkinson’s disease (Zigmond and Smeyne 2014, Dhami et al. 2015, Maraz et al. 2015, Monteiro-Junior et al. 2015). Musical accompaniment in dancing may be a powerful stimulus of neural plasticity (Altenmüller and Schlaug 2013). Pleasant musical experiences are associated with a rise in serotonin. This may be important to promote neurogenesis (Blum and Lesch 2015), evoke feelings of satisfaction (Altenmüller and Schlaug 2013) and improve anxiety and depression symptoms in those with Parkinson’s disease (Blum and Lesch 2015). Music induced dopamine activity in the mesolimbic system may alleviate some affective disorders associated with Parkinson’s disease (Blonder and Slevin 2011, Altenmüller and Schlaug 2013), improve learning and memory and stimulate emotional states of reward and pleasure (Altenmüller and Schlaug 2013).

2.4 Conclusion

Irish set dancing in an enjoyable form of physical activity that has social, emotional and creative elements that afford benefits to mobility and wellbeing. It is arguably beneficial for people living with Parkinson’s disease. The implementation of successful arts health set dancing programmes could benefit from greater engagement between the arts and health communities as well as shared plans and
perspectives. The integration of historical, health and structural knowledge that we have provided in this chapter helps to link the world of health and arts. Contextualising and translating this information within the dimension of set dancing for health and rehabilitation is imperative to foster the sense of cohesion, enjoyment and benefit that have paralleled set dancing experiences and fortified its popularity.

2.5 Epilogue

Arts and health programmes are emerging as novel therapeutic interventions for some people with Parkinson’s disease and represent a growing area in health literature. Notably, the combined perspectives of the arts and health disciplines have been little discussed in the health literature, despite their critical contribution to participatory experiences, rehabilitation outcomes and dance interventions. Therefore, this chapter discussed creative aspects and potential health benefits which may be pertinent to the therapeutic and rehabilitation role of set dancing. This trans-disciplinary approach may provide education and bring the health and arts disciplines together to further their knowledge and foster collaborations. The model used in this chapter is also transferable to other dance genres and may aid future research in the area of therapeutic dance.

This chapter successfully identified creative aspects of set dancing and their therapeutic application for improving health in those with Parkinson’s disease. This information will inform the design of the set dancing intervention that will be examined in the feasibility study and pilot RCT as part of this research. The trans-disciplinary knowledge gained from reviewing the combined perspectives of the arts and health disciplines along with the evidence-based recommendations for implementing classes for people with Parkinson’s disease will also be used to facilitate social aspects of the set dance intervention and guide the selection of dance material.

This chapter identified potential health benefits associated with set dancing for people with Parkinson’s disease including balance and quality of life benefits. As
such, validated outcome measures designed to assess these dimensions of health may be employed in subsequent phases of this research.
Chapter 3

Dance for People with Parkinson’s Disease: What is the Evidence Telling Us?

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

- Systematic review
- Narrative review
- Feasibility study
- Pilot RCT
- Dissemination
3.0 Prologue

This chapter contains a systematic review of the literature that investigated the benefit of dance for people with Parkinson's disease. The aim of this review was to appraise and synthesise the existing peer-reviewed research evidence to provide an appropriate dosage of dance for people with Parkinson’s disease using the FITT principle (Power and Clifford 2013). Additionally, this review aimed to identify gaps in the current literature in order to inform future studies. In the way, the findings of this review provide an evidence-based underpinning to inform the methods of the feasibility study and subsequently the multi-centered pilot RCT presented in Chapter 4 and 5 of this thesis. The research article based on this review was published in *Archives of Physical Medicine and Rehabilitation* (Shanahan et al. 2015b).

3.1 Introduction

Parkinson’s disease is a progressive neurodegenerative (Goetz et al. 2004) disease estimated to affect six million people worldwide (Morris et al. 2010). People with Parkinson’s disease can present with movement disorders (Keus et al. 2004), postural instability, reduced mobility and an increased risk of falls (Keus et al. 2007). The severity of Parkinson’s disease can be classified according to the original or modified Hoeln and Yahr scale with lower stages on these scales representing milder disease states (Goetz et al. 2004). At stages 1-2 physical symptoms are predominantly unilateral however as the stage of disease progresses physical symptoms become bilateral (Goetz et al. 2004). Dance has been advocated as one form of exercise for people with Parkinson’s disease (Earhart 2009), especially for those who are newly diagnosed or who have mild to moderate disease severity. Dance interventions for people with Parkinson’s disease can sometimes have a positive effect on balance, mobility (Duncan and Earhart 2012) and may help improve quality of life (Hackney and Earhart 2009b) by reducing symptoms of depression (Soh et al. 2011, Kiepe et al. 2012). Research has also found that dance is superior to exercise for improving balance and functional mobility (Hackney et al.
2007b) in some people with Parkinson’s disease. Dance may help maintain motor performance (Kattenstroth et al. 2010) and facilitate long-term compliance with physical activity as it incorporates socialisation and care-giver participation, which helps to motivate people with Parkinson’s disease to engage in physical activity (Ravenek and Schneider 2009, Crizzle and Newhouse 2012).

Earhart (2009) provided a valuable review consolidating evidence on several aspects of dance in people with Parkinson’s disease. However, since 2009 a number of studies have been published in this area and research protocols have differed in terms of the FITT principle used. Additionally, the methodological quality of studies that investigated dance interventions for people with Parkinson’s disease has not been evaluated. The lack of evidence-based dance prescription renders it difficult to translate research into clinical practice. The primary aim of this paper is to:

1. critically appraise peer-reviewed literature that has investigated the benefit of dance for people with idiopathic Parkinson’s disease
2. provide information regarding a FITT principle (Power and Clifford 2013) for people with Parkinson’s disease

The FITT principle provides a framework for reviewing the effectiveness of physical activity programmes and enables specific guidelines to be established regarding the optimum characteristics of exercise programmes (Power and Clifford 2013). The secondary aim of this paper is to identify limitations in current peer-reviewed research in order to ensure that the design, methodological quality and reporting of future unpublished studies adds to the body of existing literature and addresses gaps in the research.
3.2 Methods

3.2.1 Inclusion criteria

Only articles meeting all of the inclusion criteria listed in Table 3.1 were included in this review:

<table>
<thead>
<tr>
<th>Table 3.1 Inclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer-reviewed and published in the last 15 years.</td>
</tr>
<tr>
<td>Study participants must have been diagnosed with idiopathic Parkinson’s disease. All stages of disease were included. For comparability purposes, stage of disease must have been measured using the Hoeln and Yahr Scale or modified Hoeln and Yahr.</td>
</tr>
<tr>
<td>Included more than one participant.</td>
</tr>
<tr>
<td>Evaluated the outcome of a dance intervention for people with Parkinson’s disease.</td>
</tr>
<tr>
<td>Described the dance intervention and FITT principle used and reported the effect that the dance intervention had on one of more of the primary or secondary outcomes of interest.</td>
</tr>
</tbody>
</table>

3.2.2 Literature search

An electronic literature search of eight databases was conducted in April 2014 (AMED, MEDLINE, CINAHL Plus, SPORTDiscus, Sage, ScienceDirect, Pubmed and Pubmed Central). The search terms used were “Parkinson’s disease” AND “dance”. The suitability of articles was determined in a staged process by two reviewers (JS and AC). First, titles and abstracts were read and articles that were obviously unrelated to this review were excluded. Remaining articles were read in full and those not meeting all inclusion criteria were excluded. The reference lists from suitable articles were also searched. Any disagreements between reviewers were resolved through discussion. A detailed description of the search process is provided in Figure 3.1.
Figure 3.1 Search Strategy Based on PRISMA Flow Diagram

Identification

Records identified through database searching (n = 2022)

Records published ≤ 15 years (n = 1309)

Records identified from reference lists (n = 1)

Screening

Records screened by title (n = 1309)

Records excluded (n = 1265): reasons: duplicate, intervention not dance, study design, diagnosis

Records screened by abstract (n = 43)

Records excluded (n = 25): reasons: intervention not solely dance

Eligibility

Full-text articles assessed for eligibility (n = 17)

Records excluded (n = 5): reasons: ineligible outcomes, diagnosis

Included

Studies included in qualitative synthesis (n = 13)

Records identified from reference lists (n = 1)

Studies included in quantitative synthesis (meta-analysis) (n = 5)
3.2.3 Data extraction

Articles meeting all of the inclusion criteria were reviewed to extract relevant details of the intervention (mode of delivery, FITT principle implemented) and the outcomes used to assess the effect of the intervention. In addition, data regarding the age and stage of disease of participants involved in the studies, number of drop-outs, attendance rates and the safety of the dance interventions (monitoring and reporting of adverse events) were also extracted.

3.2.4 Outcomes of interest

The outcomes reviewed in this study were chosen so that the benefit of dance for people with Parkinson’s disease was assessed at the three levels of the International Classification of Functioning, Disability and Health (ICF). These levels are body structure and function, activity and participation (Dibble et al. 2010). The primary outcomes of interest were balance function measured on the Berg balance scale (Qutubuddin et al. 2005, Steffen and Seney 2008), motor impairment measured using the Unified Parkinson’s disease rating scale subsection-3 (UPDRS-3) (Metman et al. 2004, Steffen and Seney 2008) and functional mobility measured using the timed up and go test (Steffen and Seney 2008). Secondary outcomes of interest were endurance assessed using the six-minute walk test (Enright 2003, Falvo and Earhart 2009b), quality of life assessed on the Parkinson’s disease questionnaire-39 (PDQ-39) (Jenkinson et al. 1997, Peto et al. 2001) and activity and participation as measured on the Physical activity scale for the elderly (PASE) (Washburn and Ficker 1999, Dibble et al. 2010). If studies used more than one measurement tool to assess the same outcome (primary or secondary), only information regarding the measurement tool listed was reviewed (Coupar et al. 2010). If studies reported an outcome (primary or secondary) using different measurement tools than those listed (Coupar et al. 2010), the first measurement tool listed in the article was included in the review. Feasibility was measured using the drop-out and attendance rates. Safety was assessed by reviewing adverse effects reported (Mehrholz et al. 2007).
3.2.5 Quality assessment

The “Cochrane Handbook for Systematic Reviews of Interventions” (Reeves et al. 2008b) was used to define the study design. Level of evidence was graded according to the Agency for Health Care Policy Research recommendations previously described by Ritchlin et al. (2009). Two separate quality assessment tools were used to appraise the included articles due to the diversity of study designs (Bilney et al. 2003). This was done to ensure that key methodology issues associated with each type of design were considered during the appraisal process (Young and Solomon 2009). The PEDro Scale was used to measure the quality of RCT’s and quasi-randomised controlled trials (quasi-RCT). This scale is valid, reliable and evaluates a clinical trials statistical methods and internal and external validity (Sherrington et al. 2000, Maher et al. 2003, Macedo et al. 2010). The quality of cohort studies was assessed using the Newcastle-Ottawa Quality Assessment Scale for Cohort Studies. This is a reliable scale and recommended by the Cochrane Non-Randomised Studies Methods Group (Reeves et al. 2008a).

3.2.6 Data analysis

Where possible, forest plots were used to illustrate data from RCT’s/ quasi-RCT for the primary outcomes of interest (balance, motor impairment and functional mobility). Forest plots were produced by comparing between group differences for dance and control/other intervention groups using Comprehensive Meta-analysis Software. For accurate and appropriate cross study comparability, only data collected using one measurement tool was included in each forest plot analysis. The most frequently used measurement tool for each primary outcome of interest was chosen as this would give the largest representation on the effects of dance. Only an exploratory meta-analysis could be performed for each forest plot due to the variability in intervention protocols and participant characteristics. For this reason, the meta-analysis results may only be used to provide an indication of the effects of dance on the primary outcomes of interest.
3.3 Results

Thirteen articles consisting of eight RCT’s (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009b, Hackney and Earhart 2009a, Hackney and Earhart 2010, Duncan and Earhart 2012, Foster et al. 2013, Volpe et al. 2013), one quasi-RCT (McKee and Hackney 2013), and four cohort studies (Hackney and Earhart 2009c, Batson 2010, Marchant et al. 2010, Heiberger et al. 2011) met the inclusion criteria. All reported the demographic characteristics of participants and provided clear descriptions of the interventions used. Some also referenced material where a description of the intervention could be obtained (Duncan and Earhart 2012). Only two studies carried out a follow-up assessment following post intervention testing (Hackney and Earhart 2010, McKee and Hackney 2013). Table 3.2 and Table 3.3 provide a summary of the included studies and FITT principles employed.

3.3.1 Participants

The sample size of studies ranged from a minimum of 11 (Batson 2010, Marchant et al. 2010, Heiberger et al. 2011) to a maximum of 75 participants (Hackney and Earhart 2009b). All studies except one (Hackney et al. 2007a) recorded the mean age of participants which ranged from a mean of 61.6 years (minimum) (Volpe et al. 2013) to 74.4 (maximum) (McKee and Hackney 2013) (Table 3.2 and 3.3). Ten studies used the Hoeln and Yahr scale to describe participants’ stage of disease (Hackney et al. 2007a, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2009c, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, Duncan and Earhart 2012, Foster et al. 2013, McKee and Hackney 2013) and two studies used the modified Hoeln and Yahr scale (Batson 2010, Volpe et al. 2013) (Table 3.2 and 3.3). One study did not state participants’ stage of disease (Hackney et al. 2007a).
3.3.2 Frequency

Frequency was defined as the number of classes delivered per week. Eight studies provided two classes per week (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2010, Duncan and Earhart 2012, Foster et al. 2013, Mckee and Hackney 2013), two studies provided one class per week (Heiberger et al. 2011, Volpe et al. 2013), and one study provided three classes per week (Batson 2010). Two studies just stated the total number of classes provided during the intervention (ten classes in two weeks) and did not specify the exact number of classes per week (Hackney and Earhart 2009c, Marchant et al. 2010).

3.3.3 Intensity

The intensity of the intervention was not measured in any study. Two studies stated the intervention was low intensity but did not specify how this was identified (Batson 2010, Duncan and Earhart 2012). Ten studies stated the intervention was progressive but did not provide a description of how the intervention was progressed (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2009c, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, Foster et al. 2013, McKee and Hackney 2013). One study did not provide any description of the intensity used (Volpe et al. 2013).

3.3.4 Duration

In all studies duration was described as both the length of each dance class and the duration of the intervention (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2009c, Batson 2010, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, Duncan and Earhart 2012, Foster et al. 2013, McKee and Hackney 2013, Volpe et al. 2013). With respect to the length of a dance class, seven studies provided one hour classes (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a,
Hackney and Earhart 2009b, Hackney and Earhart 2010, Duncan and Earhart 2012, Foster et al. 2013), four studies provided 1.5 hours classes (Hackney and Earhart 2009c, Marchant et al. 2010, McKee and Hackney 2013, Volpe et al. 2013), one study implemented 1.15 hours classes (Heiberger et al. 2011) and another study provided classes 85 minutes long (Batson 2010).

The duration of the interventions varied between short periods of two and three weeks (Hackney and Earhart 2009c, Batson 2010, Marchant et al. 2010), medium lengths of ten to thirteen weeks (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2010, McKee and Hackney 2013) and longer durations of six to twelve months (Heiberger et al. 2011, Duncan and Earhart 2012, Foster et al. 2013, Volpe et al. 2013).

3.3.5 Type

Type was defined as the genre of dance used in each study. Tango dancing was used in nine studies (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2009c, Hackney and Earhart 2010, Duncan and Earhart 2012, Foster et al. 2013, McKee and Hackney 2013) and one of these studies stated the Tango material taught was adapted (McKee and Hackney 2013). Waltz/Foxtrot dancing was used in two studies (Hackney and Earhart 2009a, Hackney and Earhart 2009b). Contact Improvisation (Marchant et al. 2010) Irish set dancing (Volpe et al. 2013) and a modified version of Mark Morris Dance for Parkinson’s (Heiberger et al. 2011) were all investigated in single studies.

3.3.6 Feasibility and safety

The number of drop-outs in each study is shown in the Table 3.2 and 3.3. Attendance rates at classes ranged from 78% to 100% (Hackney and Earhart 2007a, Duncan and Earhart 2012). A number of studies reported participants were satisfied with the dance intervention and wished to continue classes post intervention (Hackney et al.
2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Hackney and Earhart 2010, Marchant et al. 2010). Two studies illustrated that participants preferred to attend a dance class compared with an exercise class, as almost 50% of participants in dance groups attended additional classes following post intervention testing while no one from the exercise groups attended additional classes (Hackney et al. 2007a, Hackney et al. 2007b).

The safety of the dance interventions was poorly monitored and reported. Only three studies reported they monitored for adverse effects (Batson 2010, McKee and Hackney 2013, Volpe et al. 2013). Three studies reported participants dropped out due to injuries described as knee pain (Hackney and Earhart 2009a, Hackney and Earhart 2009b) and the aggravation of long-standing sciatica (Hackney and Earhart 2009c).
<table>
<thead>
<tr>
<th>Study (level of evidence for the study design)</th>
<th>Participants</th>
<th>Drop Outs (N)</th>
<th>Stage of Disease (H&amp;Y)</th>
<th>Frequency</th>
<th>Intensity</th>
<th>Length of a Dance Class</th>
<th>Duration of Intervention</th>
<th>Type of Dance/Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mckee and Hackney (2013) (Quasi-RCT) (1b)</td>
<td>Total N=33 Tango group: N=24, mean age 68.4yrs. Education group: N=9, mean age 74.4yrs</td>
<td>Tango=1 Education=1</td>
<td>Tango=2.3 Education=2</td>
<td>2 class per week until 20 classes were completed in 10-12 weeks</td>
<td>Progressive</td>
<td>1.5 hour</td>
<td>12 weeks</td>
<td>Adapted Tango Education</td>
</tr>
<tr>
<td>Volpe et al. (2013) (1b)</td>
<td>Total N=24 Irish Set dance group: N=12, mean age 61.6yrs. Physiotherapy group: N=12, mean age 65yrs.</td>
<td>None</td>
<td>Irish Set dance group=2.2 (modified), (mean) Physiotherapy group=2.2 (modified), (mean)</td>
<td>1 class per week</td>
<td>Not stated</td>
<td>1.5 hour</td>
<td>6 months</td>
<td>Irish Set dancing Physiotherapy in line with KNGF guidelines</td>
</tr>
<tr>
<td>Study</td>
<td>Total N=62</td>
<td>Tango group: N=32, mean age 69.3yrs.</td>
<td>Control group: N=30, mean age 69yrs.</td>
<td>Only the number of participants at each stage stated</td>
<td>2 classes per week</td>
<td>Progressive</td>
<td>1 hour</td>
<td>12 months</td>
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<tr>
<td>Foster <em>et al.</em> (2013) (1b)</td>
<td>Tango group=16</td>
<td>Control group=11</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Duncan and Earhart (2012) (1b)</td>
<td>Tango group=16</td>
<td>Control group=11</td>
<td>2 classes per week</td>
<td>Low</td>
<td>1 hour</td>
<td>12 months</td>
<td>Tango</td>
<td></td>
</tr>
<tr>
<td>Hackney and Earhart (2010) (1b)</td>
<td>Partnered Tango group: N=19, mean age 69.6yrs.</td>
<td>Non-partnered Tango group: N=20, mean age 69.6yrs.</td>
<td>Partnered Tango group=7</td>
<td>Partnered Tango=2.5 (median)</td>
<td>Non-partnered Tango group=11</td>
<td>Non-partnered Tango=2 (median)</td>
<td>2 classes per week</td>
<td>Progressive</td>
</tr>
<tr>
<td>Hackney and Earhart (2009b)</td>
<td>Total N=75</td>
<td>Tango group: N=19, mean age 68.2yrs.</td>
<td>Waltz/Foxtrot group: N=19, mean age 66.8yrs.</td>
<td>Tai chi group: N=17, mean age 64.9yrs.</td>
<td>Control group: N=20, mean age 66.5yrs.</td>
<td>Tango = 5</td>
<td>Waltz/Foxtrot = 2</td>
<td>Tai chi = 4</td>
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<tr>
<td>Hackney and Earhart (2009a)</td>
<td>Total N=58</td>
<td>Tango group: N=19, mean age 68.2yrs.</td>
<td>Waltz/Foxtrot group: N=19, mean age 66.8yrs.</td>
<td>Control group: N=20, mean age 66.5yrs.</td>
<td>Tango = 5</td>
<td>Waltz/Foxtrot = 2</td>
<td>Control = 3</td>
<td>Tango group = 2.1 (mean)</td>
</tr>
</tbody>
</table>
| Hackney et al. (2007b) (1b) | Total N=19  
Tango group: N=9, mean age 72.6yrs.  
Exercise group: N=10, mean age 69.6yrs. | None | Tango group=2.3 (mean)  
Exercise group=2.2 (mean) | 2 sessions weekly until 20 sessions were completed in 13 weeks | Progressive | 1 hour | 13 weeks | Tango Exercise: (breathing, flexibility, resistance, dexterity and core exercises) |
| Hackney et al. (2007a) (1b) | Total N=38  
Parkinson Tango group: N=9  
Control Tango group: N=9  
Parkinson exercise group N=10  
Control exercise group: N=10  
Mean age not stated | None | Not stated | 2 sessions weekly until 20 sessions were completed in 13 weeks | Progressive | 1 hour | 13 weeks | Tango Exercise: (strength flexibility, chair exercises) |

N=number of participants,  H&Y=Hoeln and Yahr, level of evidence 1b=One or more randomised controlled trial
Table 3.3 Summary of Study Characteristics for Cohort Studies

<table>
<thead>
<tr>
<th>Study (level of evidence for the study design)</th>
<th>Participants</th>
<th>Drop Outs (N)</th>
<th>Stage of Disease (H&amp;Y)</th>
<th>Frequency</th>
<th>Intensity</th>
<th>Length of a Dance Class</th>
<th>Duration of Intervention</th>
<th>Type of Dance/ Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heiberger et al. (2011) (2b)</td>
<td>N=11 mean age 71.3yrs.</td>
<td>None</td>
<td>Only the number of participants at each stage stated</td>
<td>1 class per week</td>
<td>Progressive</td>
<td>1.15 hour</td>
<td>8 months</td>
<td>Modified version of Mark Morris Dance Group for Parkinson’s disease: Combined elements of ballet, jazz steps, contemporary dance, dance theatre and choreographic.</td>
</tr>
<tr>
<td>Batson (2010)(2b)</td>
<td>N=11 mean age 72.7yrs.</td>
<td>None</td>
<td>Stages 1-2.5 (modified)</td>
<td>3 classes per week</td>
<td>Low</td>
<td>85 minutes</td>
<td>3 weeks</td>
<td>Modern dance</td>
</tr>
<tr>
<td>Marchant et al. (2010) (2b)</td>
<td>N=11 mean age 71.2yrs.</td>
<td>None</td>
<td>2.4 (mean)</td>
<td>10 classes completed in 2 weeks</td>
<td>Progressive</td>
<td>1.5 hour</td>
<td>2 weeks</td>
<td>Contact Improvisation</td>
</tr>
<tr>
<td>Hackney and Earhart (2009c) (2b)</td>
<td>N=14</td>
<td>2.4 (median)</td>
<td>10 sessions were completed</td>
<td>Progressive</td>
<td>1.5 hour</td>
<td>2 weeks</td>
<td>Tango</td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
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<tr>
<td>mean age 62.2yrs.</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

N=number of participants, H&Y=Hoeln and Yahr, level of evidence 2b=other well designed trial (quasiexperimental)
Tables 3.4 and 3.5 summarize the measurement tools used in each study and the absolute changes for each measure.

With respect to the primary outcomes of interest, balance measures were reported in 11 studies (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Batson 2010, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, Duncan and Earhart 2012, McKee and Hackney 2013, Volpe et al. 2013). All 11 studies except one (Heiberger et al. 2011) reported improvements following the dance intervention. Balance was measured using the Berg balance scale (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Hackney and Earhart 2010, Marchant et al. 2010, Volpe et al. 2013), the Fullerton advanced balance scale (Batson 2010, McKee and Hackney 2013), mini-BESTest (Duncan and Earhart 2012), semi-tandem test (Heiberger et al. 2011) and the functional reach test (Hackney et al. 2007a). Motor impairment was reported in eight studies (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Marchant et al. 2010, Heiberger et al. 2011, Duncan and Earhart 2012, McKee and Hackney 2013, Volpe et al. 2013). All eight studies reported improvements in motor impairment. The Movement Disorders Society unified Parkinson’s disease rating scale subsection-3 (MDS-UPDRS 3) (Duncan and Earhart 2012) or the UPDRS-3 (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Marchant et al. 2010, Heiberger et al. 2011, McKee and Hackney 2013, Volpe et al. 2013) were used to assess motor impairment. The timed up and go test was used to assess functional mobility in nine studies (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Batson 2010, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, McKee and Hackney 2013, Volpe et al. 2013) and six of these reported improvements (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Batson 2010, Heiberger et al. 2011, Volpe et al. 2013).

With regard to the secondary outcomes of interest, endurance was assessed in five studies (Hackney and Earhart 2009a, Hackney and Earhart 2009c, Hackney and
Earhart 2010, Marchant et al. 2010, Duncan and Earhart 2012) using the six-minute walk test. Three studies reported improvements (Hackney and Earhart 2009a, Hackney and Earhart 2009c, Hackney and Earhart 2010). Improvements in quality of life were reported in three (Hackney and Earhart 2009b, Heiberger et al. 2011, Volpe et al. 2013) of five (Hackney and Earhart 2009b, Marchant et al. 2010, Heiberger et al. 2011, McKee and Hackney 2013, Volpe et al. 2013) studies that assessed this outcome. Quality of life was assessed using the PDQ-39 (Hackney and Earhart 2009b, Marchant et al. 2010, McKee and Hackney 2013, Volpe et al. 2013) and a modified version of the quality of life scale (Heiberger et al. 2011). The effect of dance on activity levels and participation was assessed in one study using the activity sort card (Foster et al. 2013). Improvements were found in these outcomes after the intervention.
Table 3.4 Outcome Measures and Results for Randomised and Quasi–randomised Controlled Trials

<table>
<thead>
<tr>
<th>Study (level of evidence for the study design)</th>
<th>Outcome measure</th>
<th>†Absolute change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mckee and Hackney (2013) (Quasi-RCT) (1b)</td>
<td>- Motor impairment (UPDRS-3)</td>
<td>-Motor impairment improved* in Tango group and worsened in education group (Tango=3.9pts, Education=2.1pts).</td>
</tr>
<tr>
<td></td>
<td>-Balance (Fullerton advance balance scale)</td>
<td>-Dynamic balance improved* in Tango group only (Tango=2.6pts, Education=1.2pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>-Functional mobility did not change in either group (Tango=0.2sec, Education=1sec).</td>
</tr>
<tr>
<td></td>
<td>-Quality of life (PDQ-39)</td>
<td>-Unchanged QoL in both groups (Tango=0.2pts)</td>
</tr>
<tr>
<td>Volpe et al. (2013) (1b)</td>
<td>- Motor impairment (UPDRS-3)</td>
<td>-Motor impairment improved more in dance group (Set dance=7.16pts, Physiotherapy=2.92).</td>
</tr>
<tr>
<td></td>
<td>-Balance (BBS)</td>
<td>-Dynamic balance improved in both groups (Set dance=10pts, Physiotherapy=4.84pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>-Functional mobility improved more in set dance group (DNA).</td>
</tr>
<tr>
<td></td>
<td>-Health related quality of life (PDQ-39)</td>
<td>-HRQoL improved in both groups (Set dance= 8.44pts, Physiotherapy= 4.97pts).</td>
</tr>
<tr>
<td>Foster et al. (2013) (1b)</td>
<td>-Activity and Participation (Activity sort card)</td>
<td>- New social activities gained* in tango group only (DNA).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Current participation and activity retention increased in Tango group only (DNA).</td>
</tr>
<tr>
<td>Study</td>
<td>Measures</td>
<td>Results</td>
</tr>
<tr>
<td>-------</td>
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<td>---------</td>
</tr>
</tbody>
</table>
| Duncan and Earhart 2012) (1b) | Motor impairment (MDS-UPDRS-3), Balance (Mini-BESTest), Endurance (6-MWT) | Improved motor impairment*(12.8pts) in Tango group only. 
- Improved dynamic balance*(DNA) in Tango group only. 
- Endurance worsened in control group. No change in Tango group (DNA). |
| Hackney and Earhart (2010) (1b) | Balance (BBS), Endurance (6-MWT), Functional mobility (TUG) | Improved dynamic balance* in both groups (partnered=3.2pts, non-partnered=2.6pts). 
- Improved endurance in both groups (DNA). 
- No change in functional mobility in both groups. |
| Hackney and Earhart 2009b) (1b) | Health related quality of life (PDQ-39) | Improvement in HRQoL* in Tango group only (DNA). |
| Hackney and Earhart (2009a) (1b) | Balance (BBS), Endurance (6-MWT), Motor impairment (UPDRS-3), Functional mobility (TUG) | Improved dynamic balance* in dance groups only (Tango=3.9pts, Waltz/Foxtrot=4pts). 
- Improved endurance* in dance groups only (Tango=59.4m, Waltz/Foxtrot=49.1m). 
- Improved motor impairment in Waltz/Foxtrot group only (4pt). Worsened motor impairment* in control group only (5pts). 
- Improved functional mobility in Tango group only (2.1sec). |
| Hackney et al. (2007b)(1b) | Motor impairment (UPDRS-3), Balance (BBS), Functional mobility (TUG) | Improved motor impairment* in both groups (Tango=8pts, Exercise=7.6pts). 
- Improved dynamic balance* in Tango group only (3.8pts). 
- Improved functional mobility in Tango group only (0.9sec). |
| Hackney et al. (2007a) (1b) | - Balance (Functional reach test) | - Improved balance in Parkinson Tango group (0.52 inch) and Parkinson’s exercise group (0.4 inch).  
- No change in balance in control Tango group.  
- Worsened balance in control exercise group (0.5 inch). |

+ Absolute change = difference between pre and post intervention results. Absolute changes only provided where change occurred. DNA = data not provided in original manuscript. pts = points, sec = seconds, inch = inches, m = meters, *= significant changes, level of evidence 1b = One or more randomised controlled trial, ASC = activity sort card, BBS = Berg balance scale, UPDRS-3 = unified Parkinson’s disease rating scale-subsection-3, MDS-UPDRS-3 = Movement Disorders Society unified Parkinson’s disease rating scale-subsection-3, 6-MWT = six-minute walk test, TUG = timed up and go test, PDQ-39 = Parkinson’s disease questionnaire-39, HRQoL = health related quality of life, QoL = quality of life, pts = points, sec = seconds, in = inches, m = meters.
<table>
<thead>
<tr>
<th>Study (level of evidence for the study design)</th>
<th>Outcome measure</th>
<th>† Absolute change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heiberger et al. (2011) (2b)</td>
<td>- Motor impairment (UPDRS-3)</td>
<td>- Improved motor impairment* (8.2pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>- Improved functional mobility (0.7sec).</td>
</tr>
<tr>
<td></td>
<td>- Balance (Semitandem test)</td>
<td>- No improvement in balance.</td>
</tr>
<tr>
<td></td>
<td>- Quality of life (Modified quality of life scale)</td>
<td>- Improved QoL (DNA).</td>
</tr>
<tr>
<td>Batson (2010) (2b)</td>
<td>- Balance (Fullerton Advance Balance Scale)</td>
<td>- Improved dynamic balance* (3.1pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>- No meaningful change in functional mobility.</td>
</tr>
<tr>
<td>Marchant et al. (2010) (2b)</td>
<td>- Motor impairment (UPDRS-3)</td>
<td>- Improved motor impairment* (5.4pts).</td>
</tr>
<tr>
<td></td>
<td>- Balance (BBS)</td>
<td>- Improved dynamic balance* (3pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>- No change in functional mobility.</td>
</tr>
<tr>
<td></td>
<td>- Endurance (6-MWT)</td>
<td>- No change in endurance.</td>
</tr>
<tr>
<td></td>
<td>- Quality of life (PDQ-39)</td>
<td>- No improvement in QoL.</td>
</tr>
<tr>
<td>Hackney and Earhart (2009c) (2b)</td>
<td>- Motor impairment (UPDRS-3)</td>
<td>- Improved motor impairment* (4.6pts).</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td></td>
<td>- Balance (BBS)</td>
<td>Improved dynamic balance* (2.8pts).</td>
</tr>
<tr>
<td></td>
<td>- Functional mobility (TUG)</td>
<td>- Improved functional mobility (2sec).</td>
</tr>
<tr>
<td></td>
<td>- Endurance (6-MWT)</td>
<td>- Improved endurance (35m).</td>
</tr>
</tbody>
</table>

*absolute change = difference between pre and post intervention results. Absolute changes only provided where change occurred, DNA = data not provided in original manuscript, *= significant changes, level of evidence 2b = other well designed trial (quasiexperimental), pts = points, sec = seconds, m = meters, BBS = Berg balance scale, UPDRS-3 = unified Parkinson’s disease rating scale-subsection-3, 6-MWT = six-minute walk test, TUG = timed up and go test, PDQ-39 = Parkinson’s disease questionnaire-39.
3.3.7 Methodology quality

A summary of the methodological quality assessment of the RCT’s (n=8) and quasi-RCT (n=1) is presented in Table 3.6. No study was double blinded and one concealed group allocation (Volpe et al. 2013). Five of the studies scored seven out of the ten indicating good methodological quality and one study scored four (Hackney and Earhart 2009b) indicating poor quality. The methodology quality of the cohort studies (n=4) is presented in Table 3.7. No study fulfilled the comparability section or item number two of the selection category as they were all single group studies. None of the cohort studies had a follow-up assessment following the post intervention testing. Two studies did not complete full blinded assessments (Marchant et al. 2010, Heiberger et al. 2011).
## Table 3.6 Summary of Methodological Quality of Included Randomised and Quasi-randomised Controlled Trials

<table>
<thead>
<tr>
<th>Item</th>
<th>Quasi-randomised Controlled Trials</th>
<th>Randomised Controlled Trials</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mckee and Hackney (2013)</td>
<td>Volpe et al. (2013)</td>
</tr>
<tr>
<td></td>
<td>Foster et al. (2013)</td>
<td>Duncan and Earhart (2012)</td>
</tr>
<tr>
<td></td>
<td>Hackney and Earhart (2009a)</td>
<td>Hackney et al. (2007b)</td>
</tr>
<tr>
<td></td>
<td>Hackney et al. (2007a)</td>
<td></td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Random allocation</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Allocation concealment</td>
<td>×</td>
<td>√</td>
</tr>
<tr>
<td>Baseline comparability</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Blind subjects</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Blind therapists</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Blind assessors</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Adequate follow-up</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Intention-to-treat</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Between group comparisons</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Point measures and measures of variability</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Total PEDro score</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

√ = “Yes”, × = “No”  *Total Pedro score can range from 0-10 and higher scores indicated better quality
### Table 3.7 Summary of Methodological Quality of Included Cohort Studies

<table>
<thead>
<tr>
<th>Item</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Batson (2010)</td>
</tr>
<tr>
<td></td>
<td>Hackney and Earhart (2009c)</td>
</tr>
<tr>
<td></td>
<td>Heiberger <em>et al.</em> (2011)</td>
</tr>
<tr>
<td></td>
<td>Marchant <em>et al.</em> (2010)</td>
</tr>
<tr>
<td>Selection:</td>
<td></td>
</tr>
<tr>
<td>Representativeness of the exposed cohort?</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Selection of the non-exposed cohort?</td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td>Ascertainment of exposure?</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Demonstration that outcome of interest was not present at start of study?</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Comparability:</td>
<td></td>
</tr>
<tr>
<td>Comparability of cohorts on the basis of design or analysis?</td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td>Outcome:</td>
<td></td>
</tr>
<tr>
<td>Assessment of outcome?</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td>Was follow-up long enough for outcomes to occur?</td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td></td>
<td>×</td>
</tr>
<tr>
<td>Adequate follow-up of cohorts?</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>√</td>
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<tr>
<td></td>
<td>√</td>
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<tr>
<td></td>
<td>√</td>
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<tr>
<td>Total score</td>
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<td></td>
<td>5/8</td>
</tr>
<tr>
<td></td>
<td>4/8</td>
</tr>
<tr>
<td></td>
<td>4/8</td>
</tr>
</tbody>
</table>

√ = “Yes”, × = “No”
3.3.8 Effect of dance on primary outcomes of interest

Forest plots were developed to evaluate the effect of dance on the primary outcomes of interest (balance, motor impairment and functional mobility). Findings are presented in Figures 3.2, 3.3 and 3.4 respectively. Only RCT’s and quasi-RCT’s that used the Berg balance scale, UPDRS-3 and timed Up and go test were included in the forest plots. These measurement tools were chosen as they were frequently used to assess the primary outcomes of interest.
3.4 Discussion

There is emerging level 1b and 2b evidence to suggest that multidimensional benefits are sometimes achieved through dance in people with mild to moderately-severe Parkinson’s disease. The findings of this review have found that improvements in balance (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Batson 2010, Hackney and Earhart 2010, Marchant et al. 2010, Duncan and Earhart 2012, McKee and Hackney 2013, Volpe et al. 2013), motor impairment (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009c, Marchant et al. 2010, Heiberger et al. 2011, Duncan and Earhart 2012, McKee and Hackney 2013, Volpe et al. 2013) and endurance (Hackney and Earhart 2009a, Hackney and Earhart 2009c, Hackney and Earhart 2010) were reported following participation in dance. The impact of dance programmes for those with severe stages of disease have not been investigated. Thus, the conclusions of this review may not be appropriate to implement in a population of individuals with severe Parkinson’s.

The majority of measurement tools used in the included studies were valid, reliable and sensitive to change (Jenkinson et al. 1997, Washburn and Ficker 1999, Peto et al. 2001, Enright 2003, Metman et al. 2004, Brusse et al. 2005, Qutubuddin et al. 2005, Steffen and Seney 2008, Falvo and Earhart 2009b, Dibble et al. 2010, Klein et al. 2011, King et al. 2012, Keus et al. 2014). The only exceptions were the semi-tandem test, MDS-UPDRS-3, activity sort card and modified version of the quality of life scale. To the authors’ knowledge the semi-tandem Test is usually performed as part of a battery of tests rather than as a single balance test (VanSwearingen and
Brach 2001). The MDS-UPRDS-3 (Keus et al. 2014) and activity sort card (Katz et al. 2003) are valid and reliable but the sensitivity of these measures have not yet been established. Reliability and validity of the original version of the quality of life scale has been established (Burckhardt and Anderson 2003) but no literature was found examining the psychometric properties of the modified version of the quality of life scale.

3.4.1 Frequency

The majority of level 1b evidence reviewed supports the implementation of two dance classes per week (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2010, Duncan and Earhart 2012, Foster et al. 2013). Significant improvements were found in balance (Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2010, Duncan and Earhart 2012, Mckee and Hackney 2013), motor impairment (Hackney et al. 2007b, Duncan and Earhart 2012, Mckee and Hackney 2013), endurance (Hackney and Earhart 2009a), quality of life (Hackney and Earhart 2009b) and participation in social activities (Foster et al. 2013) following attendance at two weekly classes. Only one RCT did not report a reduction in motor impairment for a dance group after this frequency of classes (Hackney and Earhart 2009a). The reason for this conflicting result is difficult to ascertain, as characteristics of participants and elements of the FITT principle were similar to a study that reported significant improvements (Hackney et al. 2007b). However, failure to carry out an intention-to-treat analysis may have caused either over or under-estimation of results.

There was a limited amount of level 1b and 2b evidence reviewed that investigated the benefit of lower and higher frequencies of dance classes per week. With respect to lower frequencies, only two studies (one RCT and cohort study) (Heiberger et al. 2011, Volpe et al. 2013) implemented one class per week. For the majority, findings were positive with greatest impact achieved in motor impairment and quality of life when course of treatment was longer (Heiberger et al. 2011, Volpe et al. 2013). Results were conflicting for balance as one study reported no improvement
(Heiberger et al. 2011). Notably, the sole use of the semi-tandem test as a balance measure and the dance type used may have influenced results.

The benefit and feasibility of a high frequency dance intervention cannot be fully established based on the existing literature. The findings from two of the three included short duration studies (level 2b evidence) suggest that a high frequency of dance classes per week may lead to greater improvements in functional mobility (Hackney and Earhart 2009c) and motor impairment (Hackney and Earhart 2009c, Marchant et al. 2010). It is currently not known if a longer duration, high frequency dance class would lead to a greater magnitude of improvement, thus further research is necessary.

3.4.2 Intensity

The lack of detail reported may be problematic for clinicians who seek clarity regarding an optimum and safe intensity to use when implementing dance programmes. Methods of measuring intensity such as scales of exertion have been recommended for monitoring and reporting the intensity of endurance and strength training in older adults (Chodzko-Zajko et al. 2009). When these scales are implemented, the desired exercise level is achieved by instructing patients to exercise at a level of exertion that is equivalent to a particular number on a scale of zero to ten (Chodzko-Zajko et al. 2009). While this method of measurement may be suitable for individual forms of exercise, it is difficult to implement in dance, as each individual’s performance intensity is synchronised to the tempo of the music. For safety the tempo of the music is usually set to ensure that individual’s with the highest level of impairment are able to participate without increasing the risk of falls and thus intensity may be progressed in line with participants abilities. The progressive nature of the dance interventions were described in the majority of studies (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2009c, Hackney and Earhart 2010, Marchant et al. 2010, Heiberger et al. 2011, Foster et al. 2013, McKee and Hackney 2013) and is necessary to ensure that gains are obtained (Power and
Clifford 2013). This suggests that tempo and intensity can be increased once the dance movements (motor skill) have been acquired and can be performed safely.

3.4.3 Duration

There was little variation in the length of classes (1-1.5 hours) (Table 3.2 and 3.3). Currently, the majority of literature supports the use of one hour classes. There is limited evidence to suggest that 1.5 hour classes may be more beneficial but more RCT research is needed to confirm this due to inconsistencies and confounders present in studies (Hackney and Earhart 2009c, Marchant et al. 2010, McKee and Hackney 2013, Volpe et al. 2013). Additionally, the frequency of weekly classes may be an important consideration. More than one class per week may be needed to accompany shorter class durations in order to enhance gains (Chodzko-Zajko et al. 2009).

Duration of the dance interventions ranged from two weeks (Hackney and Earhart 2009c, Marchant et al. 2010) to 12 months (Duncan and Earhart 2012, Foster et al. 2013). The majority of programmes were 10-13 weeks long (Hackney et al. 2007a, Hackney et al. 2007b, Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2010, McKee and Hackney 2013). Longer duration interventions may be more beneficial with greater improvements evident in balance (Hackney et al. 2007b, Hackney and Earhart 2009a, Duncan and Earhart 2012, Volpe et al. 2013) and motor impairment (Hackney et al. 2007b, Heiberger et al. 2011, Duncan and Earhart 2012, Volpe et al. 2013). Results are inconsistent for endurance as the longest duration study failed to report improvement (Duncan and Earhart 2012). This conflicting result may be partly explained by participants’ higher stage of disease (mean=2.6) and suggests improvements may be harder to achieve in individuals with more advanced disease. Nonetheless, a FITT principle of two, one hour classes per week for 12 months was sufficient to maintain baseline endurance, as demonstrated by the significant deterioration in the control group (Duncan and Earhart 2012).
It is difficult to determine the influence of duration on outcomes for functional mobility due to the variability of results and potential influence of frequency on results.

From the literature reviewed, inadequate evidence exists to support the use of dance for improving health related quality of life due to conflicting results (Hackney and Earhart 2009b, Marchant et al. 2010, Heiberger et al. 2011, McKee and Hackney 2013, Volpe et al. 2013) Overall, it appears a higher dosage of dance activity may enhance quality of life through increased participation (Hackney and Earhart 2009b, Heiberger et al. 2011, Volpe et al. 2013) but a greater body of research is required before more substantiated recommendations can be established.

3.4.4 Type

The evidence from this small number of articles showed Tango to be a beneficial dance genre for people with Parkinson’s disease. Both long and short duration Tango interventions reduced the severity of motor impairment and improved balance, functional mobility, endurance, activity and participation and quality of life. Tango is proposed to target movement disorders associated with Parkinson’s disease as it incorporates dynamic balance, continuous movement initiation and termination in multiple directions, and rhythmic and speed variations (Hackney et al. 2007b, Hackney and Earhart 2009a). Limited evidence suggests other forms of dance may be beneficial for people with Parkinson’s (Table 3.2 and 3.3). Greater improvements in motor impairment were reported following participation in Waltz/Foxtrot compared to Tango (Hackney and Earhart 2009a) and Contact Improvisation may be as effective as Tango for improving balance and motor impairment (Marchant et al. 2010) It is difficult to compare the effectiveness of Tango to other dance genres as only sparse, lower quality evidence exists to support their use. Additionally, there was variability in the FITT principles used making comparison difficult. More research is warranted to establish the benefit of other dance interventions including cultural and regional dance forms that may have additional meaning for some people. Different forms of dance may target different clinical features of Parkinson’s
disease due the variation between dance genres cognitive demands, stepping strategies and musical input. (Hackney and Earhart 2009a, Marchant et al. 2010, Heiberger et al. 2011).

3.4.5 Effect of dance on primary outcomes of interest

The forest plot representation of data indicates dance can improve balance and motor impairment in people with Parkinson’s disease. Dance was found to be more effective than a control intervention for improving balance and motor impairment (Hackney and Earhart 2009a) (Figure 3.2 and 3.3). This may help to reduce the risk of falls in people with Parkinson’s disease and have positive implications on quality of life respectively (Robinson et al. 2005, Rodriguez-Violante et al. 2015). There is also evidence to suggest that dance is more effective than traditional exercise (Hackney et al. 2007b) and physiotherapy (Volpe et al. 2013) with greater benefit evident for motor impairment (Figure 3.3). With respect to functional mobility, there is currently no evidence to suggest dance is more effective than a control/other intervention (Figure 3.4). As previously stated this may be due to insufficient weekly dosage or the relatively short duration of included studies.

The heterogeneous study protocols and participant characteristics make is impossible to accurately interoperate the meta-analysis results. However, they do indicate the potential benefits of dance and suggest future research is necessary to enable a comprehensive meta-analysis to be conducted.

3.4.6 Feasibility

Dance can be a feasible and acceptable form of exercise for some people with Parkinson’s disease. Studies investigating different dance genres reported similar drop-out rates in both dance and control groups (Hackney and Earhart 2009a, Hackney and Earhart 2009b, Hackney and Earhart 2010). Furthermore, there were no drop-outs in six studies (Hackney et al. 2007a, Hackney et al. 2007b, Batson 2010, Marchant et al. 2010, Heiberger et al. 2011, Volpe et al. 2013). The high attendance rates and participants’ requests to continue classes indicates that dance may be
feasible long-term. However, the safety of dance programmes has not been fully examined. Studies that report and monitor adverse events on a larger sample of people with Parkinson’s disease are needed. This will help clinicians determine the suitability of an individual for a particular intervention.

The results of this review suggest that a lower frequency of classes per week might enhance compliance. No participants dropped out of an eight month intervention that had one weekly class (Heiberger et al. 2011) while 50% of participants dropped out of a 12 month intervention that provided two classes per week (Duncan and Earhart 2012, Foster et al. 2013). A possible explanation for this may be travel difficulties (Hackney and Earhart 2009a). Prescribing a dance home exercise programme in addition to attending a dance class may be one initiative to help promote adherence while also increasing physical activity levels in line with the recommendations for weekly physical activity (Chodzko-Zajko et al. 2009). Research has shown that home exercise programmes are feasible and beneficial (Nocera et al. 2009, Pickering et al. 2013) with compliance rates of 79% (Pickering et al. 2013). They can be performed safely in the home when clear instructions are given and a practice session with clinicians is attended before commencing (Nocera et al. 2009).

3.5 Limitations

There are limitations associated with this review. Consequently, the recommendations outlined may offer preliminary guidance and should be implemented with caution. Seven of the included articles were carried out in a homogenous study location. This may potentially reduce the clinical transferability of findings until more multi-centered RCT’s are conducted. The low number of included studies along with the small sample size in some articles means the population of those with Parkinson’s disease may not be fully represented by results.

In terms of methodological quality, all studies had an increased risk of bias; even RCT’s with high PEDro scores (Table 3.6). The main methodological limitations present in the RCT’s were lack of allocation concealment and therapist and participant blinding. This may lead to an increased risk of selection (Schulz and
Grimes 2002) and performance bias (Agabegi and Stern 2008). However, it should be noted that performance bias may be present in all intervention studies as it is impossible to blind therapists and participants to group allocation. In addition, one study had a risk of detection bias (Hackney and Earhart 2009b) as it did not state if assessors were blinded. Two studies did not carry out an intention-to-treat analysis (Hackney and Earhart 2009a, Hackney and Earhart 2009b) and participants were not comparable for all baseline characteristics in a further two studies (Hackney et al. 2007a, Hackney and Earhart 2009b).

With respect to the included cohort studies, the non-randomised, uncontrolled study design increases the risk of selection bias. This means confounders may go unrecognised (Agabegi and Stern 2008) and makes it difficult to determine the true benefit of treatment (Norris and Atkins 2005). Detection bias may be present in two studies due to inadequate blinding of assessors (Marchant et al. 2010, Heiberger et al. 2011). On the contrary, cohort studies allow preliminary data to be collected on the effect of a treatment. Future studies need to consider methodology limitations present in the current literature and ensure that research gaps are investigated analytically.

### 3.6 Conclusion and Future Directions

Participation in dance classes may be beneficial for some individuals with mild-to-moderate Parkinson’s disease. This review provides preliminary guidance regarding an optimum FITT principle. It has highlighted methodological limitations and gaps in current literature to help inform future research development.

The results of this review found level 1b and 2b evidence to suggest that two, one hour dance classes per week, for at least ten weeks can have positive effects. Greater benefit might also be seen with longer duration interventions. A variety of dance types appear helpful including Tango, Contact Improvisation and Waltz/Foxtrot. However, not all forms of dance have been investigated. To date much of the research has focused on Tango. More high level multi-centered RCT, with robust methodology are needed to determine the effect of different types of dance and their
long-term benefit for people with Parkinson’s disease. Additionally, the safety of dance programmes needs to be adequately reported to ensure the safe and appropriate implementation of dance interventions.

### 3.7 Epilogue

The systematic review contained in this chapter successfully appraised and synthesised the literature on dance interventions for individuals with Parkinson’s disease. The findings from the quality appraisal identified methodological limitations in a number of studies; including lack of allocation concealment and blinding of assessors. The methodological limitations identified in the current literature will be considered during the subsequent stages of this research project in order to increase the reliability and validity of the results and ensure that high quality research is

These results of this review present information regarding an appropriate FITT principle for those with Parkinson’s disease involved in dance classes. Currently, the majority of evidence evaluated supports the implementation of two, one hour dance classes per week over ten to thirteen weeks. However, there is also limited evidence to suggest that other programme characteristics such as 1.5 long dance classes may be beneficial. These results will provide guidance during the development of the set dancing intervention in the feasibility study and subsequently the pilot RCT.

This review identified a number of gaps in current literature. It appears research is needed to examine the feasibility and benefit of a dance-based home exercise programme. A dance-based home programme may help overcome long-term attendance difficulties at two dance classes per week. Further research is also needed to confirm the benefit of many dance genres, including set dancing, for those with Parkinson’s disease. Therefore, the research described in the remainder of this thesis will inform the gaps identified in the literature.

Since the completion of this review in 2014, seven studies consisting of two RCTs (Duncan and Earhart 2014, Rios-Romenets et al. 2015), one quasi-RCT (Hashimoto
et al. 2015), one case-controlled study (McNeely et al. 2015c) and four cohort studies (Batson et al. 2014, Hackney and McKee 2014, Blandy et al. 2015, Westheimer et al. 2015) have been published. Methodological limitations including unblinded assessments (Batson et al. 2014, McNeely et al. 2015c, Rios-Romenets et al. 2015, Westheimer et al. 2015) and small sample size were evident in some studies (Batson et al. 2014, Duncan and Earhart 2014, Hackney and McKee 2014, Blandy et al. 2015, McNeely et al. 2015c, Rios-Romenets et al. 2015, Westheimer et al. 2015). However, the research location was more heterogeneous than reported in the systematic review. This increases the generalisability of results. The FITT principle used in studies was similar to the results of the systematic review. The majority of studies employed two one hour Tango classes per week (Duncan and Earhart 2014, Hackney and McKee 2014, Blandy et al. 2015, McNeely et al. 2015c, Rios-Romenets et al. 2015, Westheimer et al. 2015). There was greater variability in the duration of studies which ranged from four weeks (Blandy et al. 2015) to two years (Duncan and Earhart 2014). In terms of the results, balance (Batson et al. 2014, Hackney and McKee 2014, Hashimoto et al. 2015, McNeely et al. 2015c, Rios-Romenets et al. 2015), motor function (Duncan and Earhart 2014, McNeely et al. 2015c, Rios-Romenets et al. 2015, Westheimer et al. 2015) and functional mobility (Batson et al. 2014, Hashimoto et al. 2015, McNeely et al. 2015c, Rios-Romenets et al. 2015) all appear to benefit from dance. Results for endurance are more variable as a 12 week study reported improved endurance (McNeely et al. 2015c) while Duncan and Earhart (2014) reported no change after two years. Quality of life only improved in one (Blandy et al. 2015) of the four studies that assessed this outcome (Blandy et al. 2015, Hashimoto et al. 2015, McNeely et al. 2015c Westheimer et al. 2015). Notably, Blandy et al. (2015) was the only study that used the ED-VAS. This result suggests dance may improve non Parkinson's specific aspects of quality of life. The findings also indicate that dance may be more effective than exercise or a control to improve balance and functional mobility (Duncan and Earhart 2014, Hashimoto et al. 2015, Rios-Romenets et al. 2015). Tango may also be more beneficial than a dance form called “Dance for Parkinson's Disease” to improve motor function and functional mobility (McNeely et al. 2015c), however, further evidence is needed to support this finding.
Chapter 4

Is Irish set dancing feasible for people with Parkinson’s disease in Ireland?

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

Narrative review  Systematic review

Feasibility study

Pilot RCT

Dissemination
4.0 Prologue

As identified in Chapter 1, research investigating the benefit of Irish set dancing for people with Parkinson's disease is only in its infancy and more research, particularly in the Irish population, is needed to enhance the literature in this area. As a pre-requisite to the multi-centered pilot RCT, it was necessary to first examine the feasibility and safety of set dancing for people with Parkinson’s disease in Ireland. The aim of the feasibility study contained in this chapter was to determine if a set dancing programme delivered in the community is feasible for people with Parkinson’s disease in Ireland. This chapter discusses the findings of this feasibility study and methodological issues that need to be considered in the development of the multi-centered pilot RCT presented in Chapter 5.

The methodology for this study was developed using the findings of the systematic review discussed in Chapter 3. Information regarding the therapeutic characteristics of set dancing, as communicated in Chapter 2, along with feedback gathered from informal discussions with potential volunteers also informed aspects of the intervention design. The research article based on this study was published in *Complementary Therapies in Clinical Practice* (Shanahan et al. 2015a).

4.1 Introduction

Parkinson’s disease is a movement disorder characterised by bradykinesia, tremor and rigidity (Morris 2000). As the disease progresses, postural instability and mobility difficulties can have a compromising effect on physical functioning (Schenkman et al. 2011, Tan et al. 2011), quality of life (Evans et al. 2011, Nutt et al. 2011), and social engagement (Bloem et al. 2004). Physical activity is advocated in the management of Parkinson’s disease (Speelman et al. 2011) but it is estimated more than 50% do not meet the recommended activity levels (Earhart 2009) of 30 minutes per day (Centre for Disease Control and Prevention 2005). It is argued that an optimum exercise intervention for those with Parkinson’s disease integrates cueing strategies, balance training, focuses attention and improves physical capacity
Irish set dancing appears to be one effective form of physical activity for some people with Parkinson’s disease (Volpe et al. 2013) as it incorporates dynamic balance activities with gait and skilled movements. Movement generation may also be enhanced through musical cues (Nombela et al. 2013). Set dancing could enhance long-term compliance with physical activity as it incorporates socialisation and spousal participation, which are desirable elements required to motivate adherence to physical activity for people with Parkinson’s disease (Ravenek and Schneider 2009, Crizzle and Newhouse 2012). A recent study identified six months of set dancing improved balance and mobility to a greater extent than traditional exercise in a sample of Venetians with Parkinson’s disease (Volpe et al. 2013). Whilst this study showed the feasibility and benefit of set dancing for some people with Parkinson’s disease, the intervention was delivered in a rehabilitation setting and may not reflect the realities of everyday practice (Bowen et al. 2009). As the number diagnosed with Parkinson’s disease is expected to double by 2030 in several European countries (Keus et al. 2014), healthcare professionals need interventional studies to investigate the feasibility and acceptability of translating evidence into practice. Therefore, there is a need to investigate if set dancing is feasible in community settings. Additionally, set dancing is part of Irish heritage and has a traditional/fundamental social and cultural identity role in Irish communities. (Brennan 2001, Lynch 2011). Given the past experiences, cultural values and familiarity associated with this dance genre in Ireland (Brennan 2001, Lynch 2011), it is impossible to identify if the findings of Volpe et al (2013) are applicable to an Irish population with Parkinson’s disease. With this in mind, the overall aim of this study is to examine the feasibility and benefit of set dancing for people with Parkinson’s disease in Ireland. This study was conducted as a prerequisite to a pilot RCT to identify:

- the suitability of outcome measures to quantify change after the intervention
- if participants are willing to participate in a set dancing intervention
- aspects of the intervention participants are satisfied with and areas needing adaption
As this was a feasibility study of short duration, it was hypothesised participants would be able to partake fully in the intervention without reporting adverse effects. It was also hypothesised gains in functional exercise tolerance, balance, motor performance and quality of life would be evident after the eight weeks of set dancing classes.

**4.2 Methods**

This study was approval by the Mid-Western Regional Hospital Scientific Research Ethics Committee.

**4.2.1 Participants**

Ten participants (7 males, 3 females) were recruited through public talks where verbal and written information (Appendix B) about the study was provided. Written consent (Appendix C) was obtained from all participants prior to taking part along with approval from their general practitioner (Appendix D).

In accordance with inclusion and exclusion criteria, all participants had a diagnosis of idiopathic Parkinson’s disease, stages 1-2.5 on the modified Hoeln and Yahr scale (Batson 2010). They were able to walk three meters unaided and had a Digital Versatile Disc player to allow participation in the home dance programme. No participant had a serious cardiovascular/pulmonary condition, neurological deficit other than Parkinson’s disease, evidence of a musculoskeletal problem, issues contraindicating participation in exercise, or a cognitive or hearing problem which affected their ability to follow instructions or hear music. Participants had not taken part in regular dance classes in the six months leading up to the study (Marchant *et al*. 2010).

**4.2.2 Assessment**

Assessments took place the week before the dance classes began and the week after classes finished (Hackney *et al*. 2007b). Assessments were carried out by two
qualified health care professionals, blinded to the hypothesis of the study. A
standardised script was used for assessments. Participants were assessed at the same
time of day in all assessments to avoid fluctuations in performance (Hackney and
Earhart 2009a). They were instructed not to change their exercise habits or usual care
unless advised by their general practitioner. Participants were instructed to inform
the researcher if changes were made to any aspect of their usual care or exercise
habits. Participant’s data was eliminated if any changes were made (Hackney and
Earhart 2009b).

4.2.3 Outcome measures

The UPDRS-3 was used to assess the severity of motor impairments associated with
Parkinson's disease (Fahn et al. 1987b, Heiberger et al. 2011). Quality of life was
assessed using the PDQ-39 (Jenkinson et al. 1997). This questionnaire assesses the
impact of Parkinson's disease in eight different areas including mobility and
communication. The summary index (PDQ-SI) provides an overall score of the
impact of Parkinson’s disease on quality of life. The six-minute walk test was used
Balance was assessed using the Berg balance scale (Gobbi et al. 2009, Hackney and
Earhart 2010). All of these measures have been found valid and reliable in those with
Parkinson’s disease and have been used in previous studies investigating the benefit
of dance for individuals with Parkinson’s disease (Schenkman et al. 1997, Siderowf
et al. 2002, Metman et al. 2004, Qutubuddin et al. 2005, Hackney et al. 2007b,
Hackney and Earhart 2009b, Schenkman et al. 2011). An exit questionnaire
developed by Hackney and Earhart (2009a) was used to evaluate the intervention.
The questionnaire asked participants if they noticed improvements in different
aspects of health on a Likert scale from 1-5. Feasibility was assessed by monitoring
for adverse effects (falls, muscle soreness, excessive fatigue), participants’ verbal
feedback, attendance at classes, compliance with the home dance programme and
feedback from the exit questionnaire. Demographic information and past set dancing
experiences were collected via interview.
4.2.4 Intervention

Participants attended one set dancing class per week (Heiberger et al. 2011) for eight weeks. A day and time for class was chosen in collaboration with participants. Each class lasted 1.5 hours and took place in a community hall. Classes were led by a set dancing teacher who was also a chartered physiotherapist. Participants were encouraged to take rests and inform the instructor if they felt unwell and express opinions on class structure. Each participant with Parkinson’s disease was partnered with a spouse, caregiver or family member during the class (Hackney and Earhart 2010, Heiberger et al. 2011).

The dance class started with a warm up consisting of range of motion, aerobic and postural exercises (Woods et al. 2007, Heiberger et al. 2011). During the main part of the class participants learned various set dancing steps including the polka and reel steps (Lynch 2011). These steps were then combined with patterns of movement in a group formation to create a set. Sets including the Corofin Plain Set and the Plain Set were taught (Murphy 1995). These sets use stepping strategies similar to gait and contain turning movements that allow a partner to be used as visual cues. They also provide repetitive practice initiating and terminating movement and adjusting centre of gravity in different directions. The class ended with each couple practicing gait patterns to the music (Hackney and Earhart 2009c) and gentle flexibility exercises (Critchfield 2012). Exercises and dance material were progressed from sitting to supported standing using the back of a chair and finally to unsupported standing in line with participants abilities.

To complement classes, a set dancing-based exercise programme was performed at home for 20 minutes, twice per week. Exercises involved seated active practice of class material and mental rehearsal to facilitate learning (Rochester et al. 2010, Malouin et al. 2013) and optimise safety. A standardised interactive Digital Versatile Disc, developed by the dance instructor was given to aid learning (Jovancevic et al. 2012). Appendix E contains a PowerPoint presentation describing the methods used to develop this home programme. Compliance with the home exercise programme was monitored using a home exercise diary which can be found in Appendix F.
4.2.5 Statistical Analysis

Data was analysed using Predictive Analytics Software ("PASW") version 20. Frequency analysis was done to give a descriptive account of participants and to analyse questionnaire data. As data was non-parametric, the Wilcoxon Signed Ranks Test was used to compare pre and post intervention data. A significance level of < 0.05 was set for all statistical tests.

4.3 Results

All participants completed the study. Data from one participant was excluded from all analysis due to medication changes. The demographic profile of the remaining nine participants is presented in Table 4.1.

Table 4.1 Demographic Characteristic of Participants

<table>
<thead>
<tr>
<th>Demographic Characteristic (n=9)</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>66.66±5.87</td>
</tr>
<tr>
<td>Modified Hoeln and Yahr</td>
<td>1.5±0.5 (1, 2.5)</td>
</tr>
<tr>
<td>Gender (male/female)</td>
<td>7:2</td>
</tr>
<tr>
<td>Duration of disease (years)</td>
<td>7.3±5.96</td>
</tr>
<tr>
<td>Previous set dance experience (yes/ no)</td>
<td>43%</td>
</tr>
</tbody>
</table>

Values for age and duration of disease are mean± standard deviation.

Values for modified Hoeln and Yahr are median± interquartile range (minimum, maximum)

Table 4.2 displays the results. Quality of life (PDQ-39 scores) improved significantly. A trend toward significance was observed in motor impairment (reduced UPDRS-3 scores).
Table 4.2 Results

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Baseline (n=9)</th>
<th>Post intervention (n=9)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>UPDRS-3 (points)</td>
<td>11±7.5 (6, 25)</td>
<td>9±8 (4, 18)</td>
<td>0.05</td>
</tr>
<tr>
<td>PDQ-39 (points)</td>
<td>23.30±17.46 (4.59, 36.82)</td>
<td>19.27±15.93 (2.08, 31.41)</td>
<td>0.01*</td>
</tr>
<tr>
<td>6MWT (meters)</td>
<td>388.43±100.24 (288.19, 513.73)</td>
<td>388.43±93.98 (288.19, 476.14)</td>
<td>0.24</td>
</tr>
<tr>
<td>Berg (pts)</td>
<td>55±2.50 (52, 56)</td>
<td>56±2.50 (53, 56)</td>
<td>0.1</td>
</tr>
</tbody>
</table>

*Wilcoxon Signed Ranks Test, *= significant finding, Results are median±interquartile range (minimum, maximum), UPDRS-3=unified Parkinson’s disease rating scale subsection-3, 6MWT= six-minute walk test, Berg= Berg balance scale, An increase in 6MWT, Berg= Improvement, A reduction in UPDRS-3, PDQ-39= improvement

4.3.1 Feasibility

No adverse effects were reported during or following the study. Attendance rate at classes was 86%. Compliance with the home programme was 67%. One participant only attended 50% of classes due to work commitments and complied least with the home programme (25%). Other reasons for absence included illness unrelated to participants Parkinson’s disease and family events.

Results from the exit questionnaire showed participants enjoyed classes, noticed improvements in several aspects of health and would like to continue if more classes were offered (Table 4.3). In relation to verbal feedback, participants were happy with class structure and stated they “enjoyed all aspects of the class”. They felt material was taught in a way that suited their needs. Participants felt the home programme was “too simple” and would be more challenging if they could practice in standing. They liked listening to the music but felt mental rehearsal was unstimulating and “boring” and would have preferred to actively dance. Compliance with the home programme was affected by these issues and family events.
Table 4.3 Exit Questionnaire

<table>
<thead>
<tr>
<th>Questionnaire item</th>
<th>Median (min, max) (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I enjoyed participating</td>
<td>1, (1,1)</td>
</tr>
<tr>
<td>My balance improved</td>
<td>2, (2,4)</td>
</tr>
<tr>
<td>My walking has improved</td>
<td>2 (1,3)</td>
</tr>
<tr>
<td>My mood improved</td>
<td>3, (1,3)</td>
</tr>
<tr>
<td>My coordination improved</td>
<td>2 (1,3)</td>
</tr>
<tr>
<td>My strength improved</td>
<td>2, (2,4)</td>
</tr>
<tr>
<td>My endurance improved</td>
<td>2 (1,3)</td>
</tr>
<tr>
<td>I would continue classes if offered</td>
<td>1 (1,3)</td>
</tr>
<tr>
<td>I use ideas/skill learned in ADL’S</td>
<td>3(1,3)</td>
</tr>
</tbody>
</table>

Table illustrates median (minimum, maximum values for Likert scale from 1-5. 1=strongly agree, 2=somewhat agree, 3=neither agree nor disagree, 4=somewhat disagree, 5=strongly disagree).

4.4 Discussion

This study is novel as it is the first to examine the feasibility of community-based set dancing for those with Parkinson’s disease in Ireland. The results of this study are promising and can be used to inform the methods of a pilot RCT.

Quality of life improved significantly following the set dancing programme. Volpe et al (Volpe et al. 2013) demonstrated six months of set dancing could improve quality of life. However, the benefit of a shorter duration intervention delivered in the community had not been established. It is important to note Volpe et al (Volpe et al. 2013) reported a greater magnitude of improvement on the PDQ-39, illustrating the positive impact long term participation in set dancing can have on quality of life. In an Irish context, set dancing may improve quality of life as it gives people the opportunity to laugh, relax and participate in an integral part of social life (Lynch 2011). Therefore, set dancing may be easily accepted as a form of physical activity and the rewarding, enriching environment created by the music, social interaction and motor skill learning, may help stimulate brain chemicals such as dopamine and serotonin (Wickens et al. 2003, Kattenstroth et al. 2010, Heiberger et al. 2011). These play a fundamental role in the pathology of motor and non-motor symptoms.
that can negatively impact quality of life in those with Parkinson’s disease (Morris 2000, Jankovic 2008, Kish et al. 2008).

Set dancing involves multidirectional movements requiring continuous adaptation to surroundings. Challenging environments have been hypothesised to improve aspects of balance through repetitive exposure and activation of one or more of the postural control systems (Hirsch et al. 2003). However, no significant change in balance was detected post intervention. The small sample size in this study may account for this result. Additionally, participants had minimal balance impairment as indicated by balance results (Table 4.2). Previous literature (King et al. 2012, Godi et al. 2013), has identified that the Berg balance scale may not be sufficiently able to detect changes in individuals who have better balance performance, resulting in a ceiling effect. Future research may need to consider this and utilize other balance measures.

This was the first study to investigate the benefit of set dancing on functional endurance. While no improvements were observed, participants maintained their pre-assessment result over the trial. It is plausible that the intervention dosage was insufficient as participants only completed 130 minutes of dancing per week over eight weeks. This dosage is lower than previous studies used (Hackney et al. 2007b, Hackney and Earhart 2009a, Duncan and Earhart 2012) and does not meet the recommendations for weekly physical activity (Hirsch et al. 2011). It is also possible that a higher dosage is needed to significantly improve motor impairment (measured on the UPDRS-3) given that a trend toward improvement was observed in this study.

The results suggest set dancing is feasible for people with mild to moderate Parkinson’s disease. All participants completed the study and no adverse effects were reported. The attendance rate of 86% is comparable with previous dance studies (78%-91%) (Duncan and Earhart 2012, Volpe et al. 2013). Notably these studies had longer durations (6-12months) making direct comparison difficult. Concurrent with the high attendance rate in this study, the exit questionnaire showed all participants “extremely” enjoyed classes and noticed improvements in several aspects of health particularly in gait and endurance (Table 4.3). This is similar to
findings reported in previous dance and exercise studies (Hackney and Earhart 2008, Hackney and Earhart 2009a), although a larger number of participants in this study expressed a stronger desire to continue classes. Again, this may be due to the social, cultural context of set dancing in Irish society (Lynch 2011). Furthermore, work related commitments were the greatest factor that interfered with attendance, accounting for 40% of all absences. Future studies may need to consider the scheduling of classes to ensure allocated class times suit the lifestyle of the target population.

The feasibility of a home dance programme in conjunction with dance classes has not been extensively investigated in this population. Participants complied with 67% of the programme, completing an average of 3.59 hours of dance exercise at home over eight weeks. In comparison to previous studies, this compliance rate is lower than formerly reported (79%) (Pickering et al. 2013). Lack of motivation and challenge appeared to interfere most with compliance. In light of this, a number of modifications will need to be made to the home programme before implementation in future studies.

4.5 Conclusion and implications

Set dancing is safe and feasible for some people with mild to moderate Parkinson’s disease and may help to encourage participation in physical activity. Although, this study is limited by the small sample size and single group design, the findings raise hypothesis about the benefits of set dancing and identify issues regarding outcome measures and intervention dosage that will be addressed in a pilot RCT. This trial will be registered on clinicaltrials.gov.

4.6 Epilogue

The feasibility of a physical activity intervention depends on sustained interest, accessibility and safety. This chapter achieved its aim to investigate if community Irish set dancing is feasible and acceptable in a population of Irish adults with
idiopathic Parkinson’s disease. The results found the Irish set dancing intervention is safe and feasible to implement in the pilot RCT described in Chapter 5 of this thesis. Participants reported that they enjoyed the dance classes and attendance rates were high at 86%. Although modifications to the intervention including a longer duration and higher frequency of weekly dance activity were deemed necessary for subsequent stages of this research, the current results show set dancing may benefit quality of life and motor impairment in those with Parkinson’s disease. Longer duration interventions or a higher weekly dosage of dance activity will be considered as possible changes to intervention in the pilot RCT to maximise potential benefits and target endurance.

With respect to balance, the results of the current study suggest that the Berg balance scale may not be the most appropriate measure to use in this population. This result will influence the selection of balance measures during the development of the protocol of the pilot RCT, presented in Appendix G. Other validated balance measures with a lower ceiling effect will need to be implemented in order to determine the effect of set dancing on balance in those with Parkinson’s disease.

The dance-based home programme was one novel aspect of the intervention described in this chapter. While compliance with home programme was acceptable (67%) in this study, feedback from participants suggests that alterations in the content and complexity of the material are needed. These results will be used to enhance the home programme before implementing in the pilot RCT.
Chapter 5

Dance for Parkinson’s: a randomised controlled pilot trial of Irish set dancing compared to usual care

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

Narrative review

Systematic review

Feasibility study

Pilot RCT

Dissemination
5.0 Prologue

Chapter 4 described a single group feasibility study that was undertaken as a prerequisite to a multi-centered pilot RCT. This single group feasibility study was an important part of the research process and demonstrated the safety and acceptability of a newly developed community set dancing intervention for people with Parkinson’s disease in Ireland. The study also established the suitability of outcome measures to quantify change after the set dancing intervention. In order to build on the findings of the single group feasibility study and inform the research question it was essential to determine the feasibility of an RCT study design and compare the effects of set dancing to usual care for people with Parkinson’s disease. Therefore, this chapter presents a randomised controlled pilot trial of Irish set dancing compared to usual care. Pilot trials provide crucial information to inform the conduct of large scale RCTs. For example pilot trials can identify barriers to recruitment or problems with randomisation procedures (Tickle-Degnen 2013). Thus, the pilot trial described in this chapter was undertaken to examine the feasibility of a RCT study design including randomisation procedures, resource availability, recruitment rates and attrition levels and to provide preliminary results comparing set dancing to usual care, on specific outcome measures, in an Irish population with Parkinson’s disease. The results of this study were used to inform the content of the educational resource described in Chapter 6 and 7 of this thesis. The findings inform larger international trials examining the effectiveness of community set dancing in comparison to usual care. The protocol of this pilot trial was developed in line with Consort statement (Schulz et al. 2010) and is registered on clinicaltrials.gov (NCT01939717). The protocol is also presented in Appendix G. The research article based on this study was submitted for review for publication to Parkinsonism and Related Disorders (20 May 2016).
5.1 Introduction

People with Parkinson’s disease often seek information on which forms of physical activity have the ability to provide symptomatic relief of movement disorders and disabilities. Dancing is emerging as one form of exercise that can provide short term enhancement of movement, balance, cognition and health related quality of life (Hashimoto et al. 2015, Rocha et al. 2015, Shanahan et al. 2015b, Aguiar and Morris 2016). Depression (Grover et al. 2015), slowness of movement (Morris and Iansek 1996), freezing of gait (Tan et al. 2011) and muscle weakness (Morris et al. 2015) are common in people with Parkinson’s disease and dancing arguably helps some people to alleviate these symptoms (Blandy et al. 2015, McNeely et al. 2015a). Dance has the potential to influence cognition, mood and movement, as choreographed movement sequences are memorised and performed in coordination with musical rhythms (Dhami et al. 2015). There is growing evidence that Irish set dancing (Volpe et al. 2013, Shanahan et al. 2015a), Argentine Tango (Blandy et al. 2015, Lötzke et al. 2015) and contemporary dance (Batson et al. 2014) may be beneficial for people with Parkinson’s disease.

Irish set dancing is of particular interest for people with Parkinson’s disease as it is a rhythmical, energetic and social dance genre with the potential to cue movements, making them faster, larger and well-coordinated. Irish set dancing is a cultural and group form of dance that incorporates socialisation, aerobic activity, rhythmic stepping strategies and multi-directional movement sequences involving turning and forward and backward stepping (Murphy 2009, Shanahan et al. 2015a). Commensurate with community walking, group movement sequences require individuals to negotiate around other dancers by altering body position, and changing direction (Shumway-Cook et al. 2002, Lamont et al. 2012). Learning to set dance incorporates the principles of task-specific motor learning (Petzinger et al. 2013). Stepping strategies and group movements for Irish set dancing need to be memorised and performed in unison. The accompanying Irish music is also important, acting as a rhythmic cue to trigger and synchronise movements (Nombela et al. 2013, Ashoori et al. 2015) as well as helping to improve quality of life (Hackney and Bennett 2014).
Currently, there is limited evidence to inform the conduct of a large scale multi-centered international RCT evaluating the effectiveness of dancing for people with Parkinson’s disease. Conducting large RCTs on physical activities for people with Parkinson’s disease can be challenging (McGinley et al. 2012). Potential barriers to large RCT’s include recruiting sufficiently large samples, implementing valid randomisation and blinding procedures (Avery et al. 2014) and minimizing attrition (McGinley et al. 2012).

In preparation for international large scale randomised trials, the aims of this pilot trial are to examine:

- the feasibility of the study design, randomisation procedure and resources required (Tickle-Degnen 2013)
- if sufficient recruitment rates and acceptable attrition levels can be achieved (Tickle-Degnen 2013)
- motor impairment, balance, quality of life and functional endurance in an Irish set dancing group compared with a usual care control group

### 5.2 Methods

#### 5.2.1 Study design

We conducted a multi-centered pilot RCT with assessors blind to group allocation. Ethics approval was obtained from the University Hospital Scientific Research Ethics Committee, and the Faculty Research Ethics Committee. Study development and reporting were compiled in line with the CONSORT statement (Schulz et al. 2010) and registration details can be accessed on clinicaltrials.gov (NCT01939717).

#### 5.2.2 Participant recruitment and randomisation

Participants were recruited from Ireland, from The Parkinson’s Association of Ireland, Parkinson’s support groups, consultant neurologists, Parkinson’s clinical nurse specialists and chartered physiotherapists via flyers (Appendix H) and public
talks. Volunteers were eligible to participate if they were over 18 years, had a diagnosis of idiopathic Parkinson’s disease (Hackney et al. 2007b, Marchant et al. 2010) stage 1-2.5 on the modified Hoeln and Yahr scale (Batson 2010), able to walk independently for three meters (Hackney et al. 2007a), not pregnant and with access to a Digital Versatile Disc player or computer to enable participation in the home exercise programme. People were excluded if they had a neurological condition other than Parkinson’s (Batson 2010), cardiopulmonary or musculoskeletal conditions contraindicating participation in exercise (Lodder et al. 2004) or a cognitive or hearing problem which affected their ability to follow instructions or hear music. Participants had not taken part in set dancing classes during the six months prior to the pilot trial. All participants received an information leaflet (Appendix I) about the study and provided written informed consent (Appendix J) before taking part. In addition, a letter was sent to their medical practitioner (Appendix K) to ensure they were medical fit to participate. Where participants were recruited through Parkinson’s support agencies, letters were also sent to consultant neurologists (Appendix L).

Simple randomisation (Suresh 2011), using a sealed brown envelope system, was used to allocate eligible participants to the set dance or control group. The randomisation procedure was performed separately at each centre. This was done to ensure there was a sufficient number of participants at each centre to run a set dancing class. For each centre, an individual blinded to the hypothesis of the study prepared the envelopes by consequently placing an allocation form for each group into the envelopes. An independent mediator who otherwise was uninvolved in the study and blinded to the hypothesis of the study, was responsible for storing the sealed envelopes in an undisclosed location, generating the random allocation sequence, informing participants of their group allocation and maintaining an undisclosed record of allocation for each participant.

5.2.3 Assessments

Participants were informed of their group allocation after completing baseline assessments. Assessments took place the week before the intervention and within a
week following the dance programme completion. Participants chose a suitable testing time and every effect was made to ensure participants were assessed at the same time of the day in both pre and post intervention assessments. Assessors were blinded to group allocation. Baseline demographic information including age, gender, duration of Parkinson’s disease, previous Irish set dance experience and physical activity levels were collected. Physical activity levels were determined using the PASE (Washburn et al. 1993, Washburn et al. 1999). Participants were instructed not to change their daily activities, usual care or exercise habits unless advised by their practitioner and to report any changes to the researchers.

5.2.4 Primary outcome: Feasibility

Feasibility was appraised by quantifying:

- the success of randomisation and allocation procedures. We aimed to monitor and document issues affecting the correct implementation of the randomisation and allocation procedures (Charlesworth et al. 2013, Tickle-Degnen 2013, Avery et al. 2014)
- resources: availability and cost of buildings, dance studios and personnel (researchers, assessors, independent mediator, dance partners, dance teachers and health practitioners) were documented (Tickle-Degnen 2013, Blandy et al. 2015)
- whether or not 100 participants could be recruited in one year. This would test recruitment rates and the success of recruitment methods (Tickle-Degnen 2013)
- willingness of participants to be randomised, determined by recording the number of people that declined participation after being advised of the group they were randomised to (Arain et al. 2010, Tickle-Degnen 2013)
- attrition rates for the entire study. Attrition less than or equal to 20% per group was regarded as acceptable. This was in line with the criteria established by the Centre for Evidence Based Medicine for appraising the quality of RCTs (Centre for Evidence-Based Medicine 2005)
safety: the intervention was considered safe if no adverse effects or injuries including falls, were recorded
adherence to the Irish set dancing intervention. The intervention was considered to be successful enough to warrant further large scale international investigations if attendance at classes was ≥70% (Blandy et al. 2015)

5.2.5 Secondary outcomes

Changes in motor impairment, balance, quality of life and functional endurance were assessed using valid and reliable outcome measures (Jenkinson et al. 1997, Schenkman et al. 1997, Siderowf et al. 2002, Metman et al. 2004, Leddy et al. 2011, King et al. 2012, Godi et al. 2013). Motor impairment was assessed using the UPDRS-3 (Fahn et al. 1987a). Health related quality of life was assessed using the PDQ-39 (Marchant et al. 2010). The PDQ-39 SI score provides an indicator of the impact of Parkinson’s disease on quality of life across eight domains of health and wellbeing. Functional aerobic capacity was assessed using the six-minute walk test (Falvo and Earhart 2009a) and balance was assessed using the mini-BESTest (King et al. 2012, Godi et al. 2013). A sub-sample of participants completed an exit questionnaire at the end of the study. This questionnaire was developed by Hackney and Earhart (Hackney and Earhart 2009a) to assess participant satisfaction with the dance intervention. The questionnaire asks participants if they have noticed improvements in physical well-being since starting the programme.

5.2.6 Intervention

Participants allocated to the Irish set dancing group took part in one, 1.5 hour community Irish set dancing class each week for ten weeks (Shanahan et al. 2015b). Classes were led by Irish set dancing teachers with previous experience teaching dancing in a clinical population or by trained health professionals who were also Irish set dancing teachers. A chartered physiotherapist trained set dancing teachers in how to safely and effectively implement therapeutic dancing classes. During the classes participants partnered with spouses, family members or volunteers with Irish
set dancing experience. They were encouraged to take rests as needed or to inform the dance instructor if they felt unwell.

At the start of each class warm up exercises targeting movement speed and size, range of motion (Heiberger et al. 2011), postural alignment and physiological systems required for dance (aerobic, muscular and neuromuscular) were performed (Woods et al. 2007, Irvine et al. 2011). Exercises were progressed from sitting to supported standing using the back of a chair and then unsupported standing and moving according to abilities.

During the main part of the class participants learned the hornpipe and reel step which have some similar components to gait, with stance and swing phases. Attention was given to foot positioning and stepping rhythm. When steps were competently performed during straight line movements with a single turn, participants were then introduced to Irish set dances which combined steps and sequences of group movement patterns. Sets including the Kilfenora Set, Connemara Set and Corofin Plain Set were taught (Murphy 1995, Murphy 2009). Dance movements such as the “lead around” and “advance and retire” which feature in all the sets aforementioned, as well as “dance around partner” in the Corofin Plain Set were expected to be beneficial as they allow the movements of dance partners’ to be used as a visual cue. This may facilitate step length, movement execution and prevent festination. These movements also involve human contact which may create a sense of security for people with Parkinson’s disease. To facilitate motor skill learning, complex patterns of movements such as the “pass through” which involve independent straight line and turning movements, were broken down into simpler components before being practiced as a whole (Morris et al. 2009). Other complex movements such as the “little Christmas” were simplified and practiced as a “little circle” with four dancers holding hands and dancing to the right. The complexity of the dance material and the tempo of the music was progressed in line with the participants’ abilities (Marchant et al. 2010). Attentional focus was placed on movement quality to help enhance movement generation (Morris 2000). The class ended with each dance couple practicing a gait pattern using music as an external cue.
(Hackney and Earhart 2009c). Gentle flexibility exercises were also performed to maximise joint movement and to cool down (Critchfield 2012).

In addition to the formal dance class, participants were given a 20 minute home dance programme to complete three times a week. A standardised video interactive Digital Versatile Disc (Jovancevic et al. 2012) and Compact Disc developed by the main researcher (JS) were provided to assist warm-up exercises and practice of material taught in class. During rest periods mental rehearsal of material was advised (Malouin et al. 2013). Adherence to the home dance programme was monitored using a home exercise diary (Appendix M). Participants in the dance group also continued with their usual medication regime, daily activities and exercise habits during the 10 week dance intervention. No participant was involved in additional interventions during the study.

The control group continued with their usual care which involved medication treatment only. Participants also continued with their normal daily activities and exercise habits. No additional intervention was offered to the control group, but over 60% of participants took part in the set dance classes after completion of post intervention assessments.

5.2.7 Sample size

In this pilot trial, it is necessary to estimate the expected rate of recruitment for a larger trial. Therefore, 100 participants, approximately 25% of the sample size required to power the larger trial (394 participants to detect a four point difference in the PDQ-39) will be recruited over a 12 month period in this study. The sample size for the larger RCT was determined by a statistician using statistical analysis of data from the feasibility study described in Chapter 4 of this thesis.

5.2.8 Statistical analysis

Data were analysed using SPSS version 22. Descriptive statistics (medians and interquartile ranges) were used to describe data as most were non-normally
distributed. There were a large number of dropouts in this study. Therefore, an intention-to-treat analysis was deemed inappropriate as the results would be impossible to interpret due to the heterogeneity of the sample included (Gupta 2011). Thus, a per-protocol analysis was performed and included all participants that completed the study. This ensured against a large degree of heterogeneity associated with including data from dropouts or protocol violators in the analysis (Gupta 2011) and allowed preliminary information comparing set dancing to usual care to be gathered. The Mann-Whitney U test was used to analyse between-group data from baseline and post intervention assessments. Intragroup comparisons comparing baseline and post intervention data were analysed using the Wilcoxon Signed Ranks test. There was a small amount of missing data for the PDQ-39 for both the dance group (n=2) and control group (n=1) due to incomplete or missing questionnaires. Data were excluded from participants with changes to their Parkinson’s disease medication during the study. An alpha level of 0.05 was set for all statistical tests.

The attendance rate for dance classes was calculated as a percentage of the total number of participants that started the intervention (n=37). This ensured against falsely elevated adherence levels (Allen et al. 2012).

### 5.3 Results

During a 13 month period, ninety nine volunteers, from nine centres, were assessed for eligibility to participate in the study and ninety were randomised (n=45 per group). The flow of participants through the study is shown in Figure 5.1. Attrition over the course of the study was 46.67% in the dance group and 44.44% in the control group. The demographic profile of participants is shown in Table 5.1. There was no significant difference between the groups’ demographic data at baseline except for past dance experience. UPDRS-3, six-minute walk test, mini-BESTest and PDQ-39 were also statistically comparable at baseline, however, there was a minimal clinically meaningfully difference between the dance and control groups’ UPDRS-3 scores (median difference = 3.50 points) (Keus et al. 2014). Participants Parkinson’s disease medication included Stalevo, Sinemet and Azilect.
No adverse effects were reported during or after the study. There was no difficulty finding physical resources but there were some issues matching suitable scheduling times between buildings, assessors and participants. These were quickly resolved through schedule changes. Four dance teachers were involved in the study and delivered the intervention to participants. The cost of buildings and dance studios were feasible.
Figure 5.1 CONSORT Flow Diagram of Participants Through Study

Enrolment
- Assessed for eligibility (n=99)

Allocation
- Excluded (total n=9)
  - Not meeting inclusion criteria (n=9)
- Randomized (n=90)
- Allocated to dance (n=45)
  - Received allocated intervention (n=37)
  - Did not attend initial assessment (total n=8)
    - Family reasons (n=1)
    - Unwell unrelated to PD (n=1)
    - Travel problems (n=1)
    - No reason (n=5)
- Allocated to control (n=45)
  - Received allocated intervention (n=40)
  - Did not attend initial assessment (total n=5)
    - Unwell unrelated to PD (n=1)
    - No reason (n=4)

Follow-Up
- Lost to follow-up (did not attend post-intervention assessment (total n=6)
  - On holidays (n=2)
  - Unwell unrelated to PD (n=4)
- Discontinued intervention (total n=7)
  - Too intense (n=1)
  - No reason (n=1)
  - Did not like (n=2)
  - Family reasons (n=1)
  - Change in work schedule (n=2)

Analysis
- Analysed (n=20)
  - Excluded from analysis (total n=4)
    - Medication changes (n=4)
- Analysed (n=21)
  - Excluded from analysis (total n=4)
    - Medication changes (N=3)
    - Diagnosis of idiopathic PD under review (n=1)
Table 5.1 Demographic Profile of Participants

<table>
<thead>
<tr>
<th></th>
<th>Dance group (n=20)</th>
<th>Control group (n=21)</th>
<th>Between group (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>69 (10)</td>
<td>69 (8)</td>
<td>0.70</td>
</tr>
<tr>
<td>Modified Hoeln and Yahr</td>
<td>1.25 (1)</td>
<td>2 (1)</td>
<td>0.27</td>
</tr>
<tr>
<td>PASE</td>
<td>154.45 (106.02)</td>
<td>108.79 (114.54)</td>
<td>0.38</td>
</tr>
<tr>
<td>Disease duration (years)</td>
<td>5.5 (6)</td>
<td>6 (8)</td>
<td>0.96</td>
</tr>
<tr>
<td>Gender (male:female)</td>
<td>13:7</td>
<td>13:8</td>
<td>0.66</td>
</tr>
<tr>
<td>Previous Irish set dance experience</td>
<td>40% (n=8)</td>
<td>14.3% (n=3)</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Values for age, duration, modified Hoeln and Yahr, PASE are median (interquartile range), *Mann-Whitney U Test, *= significant finding, PASE=physical activity scale for the elderly

5.3.1 Feasibility of the Irish set dancing

Attendance at classes was excellent at 93.5%. Reasons for absences were illnesses or family events that were unrelated to Parkinson’s disease. The findings from the exit questionnaire showed that participants enjoyed participating and reported improvements in aspects of health, including mood (Table 5.2). Compliance with the home dance programme was 71.46% for those that handed back exercise diaries (n=10, 50%). Lack of time, forgetfulness, and family events affected compliance with the home dancing programme.
Table 5.2 Results of Exit Questionnaire

<table>
<thead>
<tr>
<th>Questionnaire item</th>
<th>Median (min, max) (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I enjoyed participating</td>
<td>1, (1,2)</td>
</tr>
<tr>
<td>My balance improved</td>
<td>2, (2,5)</td>
</tr>
<tr>
<td>My walking has improved</td>
<td>2, (1,5)</td>
</tr>
<tr>
<td>My mood improved</td>
<td>2, (1,4)</td>
</tr>
<tr>
<td>My coordination improved</td>
<td>2 (1,3)</td>
</tr>
<tr>
<td>My strength improved</td>
<td>2, (1,4)</td>
</tr>
<tr>
<td>My endurance improved</td>
<td>2 (1,3)</td>
</tr>
<tr>
<td>I would continue classes if offered</td>
<td>1 (1,3)</td>
</tr>
<tr>
<td>I use ideas/skill learned in classes in ADL’S</td>
<td>2, (1,4)</td>
</tr>
</tbody>
</table>

1=strongly agree, 2=somewhat agree, 3=neither agree nor disagree, 4=somewhat disagree, 5=strongly disagree

5.3.2 Results of between-group comparisons

No significant difference was observed between the groups in the PDQ-39 (pre p=0.48, post p=0.43), six-minute walk test (pre p=0.57, post p=0.33) and mini-BESTest (pre p=0.24, post 0.28) scores at baseline or post intervention. There was no significant difference between the groups baseline UPDRS-3 results (p=0.54). After the 10 week intervention a trend toward significance was observed (p=0.07) as the control group deteriorated and the dance group showed minimal signs of improvement. Figure 5.2a, 5.2b, 5.2c and 5.2d present these results.

5.3.3 Results of intragroup comparisons

Figure 5.2a, 5.2b, 5.2c and 5.2d display the results of the intragroup comparisons for the UPDRS-3, PDQ-39, six-minute walk test and the mini-BESTest for the dance and control group. Quality of life improved in both groups yet the dance group improved to a greater extent. Endurance declined in both groups during the intervention but to a much larger degree in the control group.
Figure 5.2a Pre and Post Assessments Results for the UPDRS-3 for the Dance and Control Group

Values are median±interquartile range, p=alpha level, back lines are for Wilcoxon Signed Ranks test, blue lines are baseline Mann-Whitney-U test, green lines are post intervention Mann-Whitney U test

Figure 5.2b Pre and Post Assessments results for the PDQ-39 for the Dance and Control Group

Values are median±interquartile range, p=alpha level, back lines are for Wilcoxon Signed Ranks test, blue lines are baseline Mann-Whitney-U test, green lines are post intervention Mann-Whitney U test
Figure 5.2c Pre and Post Assessments Results for the Six-minute Walk Test for the Dance and Control Group

Values are median±interquartile range, p=alpha level, back lines are for Wilcoxon Signed Ranks test, blue lines are baseline Mann-Whitney-U test, green lines are post intervention Mann-Whitney U test, 6 minute walk test=six-minute walk test
Figure 5.2d Pre and Post Assessments Results for the Mini-BESTest for the Dance and Control Group

Values are median±interquartile range, \( p = \alpha \) level, back lines are for Wilcoxon Signed Ranks test, blue lines are baseline Mann-Whitney-U test, green lines are post intervention Mann-Whitney U test

5.4 Discussion

This study showed Irish set dancing to be a feasible and safe form of physical activity for people with mild to moderate Parkinson’s disease. It also identified a small number of feasibility issues that would need to be considered when developing larger clinical trials on dancing for people with Parkinson’s. The results provide preliminary evidence comparing Irish set dancing to usual care in those with Parkinson’s disease. Health related quality of life was influenced by dancing in this sample.

The Irish set dancing intervention was found to be feasible in this sample of Irish people with Parkinson’s disease and no safety issues or adverse effects were reported. Participants reported set dancing was a motivating and enjoyable form of exercise and showed interest in continuing participation. In accordance with this only seven participants discontinued the dance classes. Attendance at classes (93.5%) was higher than reported in previous studies of comparable duration (Shanahan et al.
High adherence (91%) was also reported in a six month set dancing programme in a sample of Venetians with Parkinson’s disease (Volpe et al. 2013) and longer-duration studies are warranted in an Irish population.

In contrast to the successful and well attended dance classes, compliance with the home dance programme was not strong. Many participants reported that “they forgot” to complete the programme indicating it may not always be feasible for increasing the weekly frequency of dance activity. SMS text messaging alerts have been found to increase daily physical activity in older adults (Müller et al. 2016) and may be a suitable strategy to encourage participation with home dance programmes. Qualitative research methods may identify appropriate options for home programme scheduling or alternative approaches for increasing the weekly dosage of dance in further studies.

Recruitment rates in this pilot trial were in line with feasibility criteria, although the recruitment period took one month longer than anticipated. Resource availability was also sufficient for the current trial and for running a future large scale trial. The planned methods for randomisation and allocation procedures were also successfully implemented and baseline between-group comparability may be improved with a larger sample size. The high dropout rate raises feasibility concerns for larger trials. Retaining participation is an important issue that affects the power of RCT’s (McGinley et al. 2012). In this study the attrition rate exceeded 40% in both groups which was higher than reported in dance classes in the USA (Hackney and Earhart 2009a, McNeely et al. 2015c) and exercise studies in Australia (Canning et al. 2015). Health issues unrelated to Parkinson’s disease and family reasons accounted for a large proportion of dropouts in this study, however, some participants did not give a reason for ceasing participation. Feelings of dissatisfaction may account for dropouts in the control group as no additional intervention was offered during the study and participants were asked not to partake in this popular cultural activity (Page and Persch 2013). Pre-defined cultural perceptions may have deterred participation in the dance group as the process of research involvement may have differed from past experiences of Irish set dancing and challenged it’s accepted socio-cultural role (Brennan 2001, O’Connor 2013). Future studies may consider
alternative study designs such as non-randomised comparison studies (Harris et al. 2006) or use strategies to promote retention. McGinley and colleagues (2012) advocate that group-based patient education may be a suitable intervention to increase adherence in control groups. Continual contact with all trial participations during the study period and pre-notification for follow-up assessments may also help to encourage participation (Bower et al. 2014)

After 10 weeks of dancing, the dance group had a reduction of 4.9 point on the PDQ-39 SI. This magnitude of improvement in quality of life may be substantial as Volpe et al. (2013) reported an 8.44 point reduction in PDQ-39 scores following six months of set dancing. The social and context of Irish set dancing may improve quality of life by enhancing mood and creating a sense of social connectivity, satisfaction and reward (Schrag et al. 2000a, Jain and Brown 2001, Foley 2011, Cuypers et al. 2012, Lewis et al. 2014, Rieu et al. 2016). These are also helpful for promoting long-term compliance with physical activity (Thomas 2001). Music may supplement the therapeutic effects of dancing by modulating dopamine and serotonin (Altenmüller and Schlaug 2013), alleviating symptoms of fatigue or depression as well as improving health related quality of life (Chan et al. 2012, Hackney and Bennett 2014, de Dreu et al. 2015). Future studies could consider the effect of Irish set dancing on mood (Lewis et al. 2014) as well as social isolation (Soleimani et al. 2014) in those with Parkinson’s disease.

The results showed a small non-significant decline in motor function (UPDRS-3) in the control group while the dance group showed no meaningful improvement. Endurance deteriorated in both groups, suggesting external factors outside the study may have influenced performance of the six minute walk test. Although the deterioration in both groups was not clinically meaningfully for this population (minimal clinically important difference = 82 metres), the reduction in endurance in the control group was above the 50 meter cut-off for substantial change in older adults (Perera et al. 2006) and thus, may have some clinical relevance. Notably, the dance group experienced less than half the reduction of the control group indicating a possible protective benefit of Irish set dancing. While Irish set dancing provides aerobic exercise it is possible the intervention intensity in this study was insufficient
to improve endurance. Motor skill learning is a central part of Irish set dancing as steps and movements have be learned and automatised. Performance of newly learned motor skills must also be retained between classes. Research has found that people with Parkinson’s disease show slower rates of learning compared to age-match controls (Nieuwboer et al. 2009). In this short-term study participants spent a great deal of time learning and perfecting movement patterns. A slower musical tempo and simple unidirectional movements were also used initially to allow participants to practice, refine and consolidate precise motor sequences. Although exercise intensity progressed (music beats per minute (bpm) increased from 64 to 100 bpm) (Shanahan et al. 2015b) during the intervention, musical tempo remained approximately 20% lower than used in Irish set dancing classes for healthy adults. Longer duration interventions may be more beneficial and allow more time to automatise motor skills and increase the intensity of class (Chodzko-Zajko et al. 2009). The short duration of this study may also explain the lack of improvement in balance as participants did not get an opportunity to progress and learn a variety of turning and multidirectional movements. These movements may be a vital progression for improving balance and therefore should be implemented at a sufficient level to challenge balance without increasing the risk of falls (Power and Clifford 2013). Additionally, low compliance with the home dance programme reduced the weekly dosage of dance activity and may have impacted upon results.

The neural correlates of the preserved performance in the dance group are not completely clear. It is proposed that dance may stimulate neural processes involved in protecting and maintaining brain health (Dhami et al. 2015). The combination of music, aerobic exercise, motor skill learning, movement sequences, and rhythmic dance steps (Murphy 2000, Bremer 2007) may help to temporarily alleviate motor symptoms by encouraging synaptogenesis and protecting brain structures from oxidative stress (Zigmond and Smeyne 2014, Dhami et al. 2015). Music with dancing may module emotional processes helping to improve mood and enhance neuroplasticity (Altenmüller and Schlaug 2013, Dhami et al. 2015). As an external cue, the regular rhythmic beat of Irish dance music may also help to cope with timing deficits in the basal ganglia-supplementary motor circuits and normalise the execution of automatic movements (Rochester et al. 2013).
The modest sample size is a limitation of this study in terms of generalisability, however, this sample was sufficient to achieve the aims of the study and pilot the methods for a planned larger trial. Of note, this study identified issues affecting participant retention which are paramount to inform further trials.

5.5 Conclusion

Irish set dancing is an enjoyable form of physical activity for many people living with Parkinson’s disease. In this Irish trial, set dancing was associated with improvements in movement and health related quality of life in some individuals. Tailoring the dance intervention and support mechanisms to minimise attrition are recommended when designing future large scale RCTs to test international generalisability.

5.6 Epilogue

This study achieved its aim and described a pilot trial that investigated the feasibility of a randomised controlled study design. This study also compared community set dancing to usual care. The findings show adherence to the dancing programme in this study was high (93.5%), although, there was more than 40% attrition in each group. The identification of this feasibility issue is an important finding of the current study and emphasises the importance of conducting pilot trials. Future international studies will need to consider initiatives that help retain participants and study power.

The results show set dancing is a motivating and enjoyable form of exercise and can afford benefits for quality of life and motor function in comparison to usual care. To the author’s knowledge, this study was the first to compare community set dancing to usual care involving medication treatment only. Therefore, the findings provide novel evidence to inform the research question. These results will be considered
during the development of the educational resource (Appendix A). The methods used
to develop the educational resource are presented in subsequent chapters of this
thesis.
Chapter 6

Protocol for development and completion of educational resource booklet

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

Narrative review  Systematic review

Feasibility study

Pilot RCT

Dissemination
6.0 Prologue

Following two community-engagement conferences that disseminated the work completed in the earlier stages of this thesis, set dancing teachers identified a lack of information available to enable them implement set dancing classes for people with Parkinson’s disease. In order to address the educational needs of set dancing teachers and values of people with Parkinson’s disease, an educational resource was developed. This chapter describes the rationale and methodology for developing this educational resource. The protocol used to develop this educational resource was informed by the Centre for Disease Control and Prevention (CDC) recommendations for the creation of health communication materials (Centre for Disease Control and Prevention 2009) and the findings of this research thesis. The aim of the educational resource was to synthesise the existing evidence, including the findings of this project, in order to address the educational needs of community set dancing teachers. In this way, the educational resource should facilitate the safe and enjoyable implementation of community set dancing classes for people with Parkinson’s disease.

6.1 Introduction

Irish set dancing is a social dance genre, popular in many communities in Ireland, Europe, America and Australia (Murphy 2009, O’Connor 2013). Of late, interest in the therapeutic benefits of set dancing for those with Parkinson’s disease has escalated. In comparison to other forms of exercise such as walking or swimming, set dancing offers variable and creative bodily movement, musical cueing, augmented postural challenges and increased social interaction (Murphy 2000, Foley 2011, Shanahan et al. 2015a). Research has found set dancing can improve quality of life, motor function and mobility in some people with Parkinson’s disease (Volpe et al. 2013, Shanahan et al. 2015a). Set dancing also appears to stimulate regular participation as evidenced by high attendance rates, participants’ subjective satisfaction and motivation to take part in future classes (Volpe et al. 2013, Shanahan et al. 2015a). Moreover, no participant dropped out of an eight week
(Shanahan et al. 2015a) or six month set dancing programme (Volpe et al. 2013) and a similar number of participants discontinued set dancing or usual care in the ten week pilot RCT described in Chapter 5. This suggests set dancing may encourage a more active lifestyle and help maintain quality of life (Duncan and Earhart 2011) and functionality (van Nimwegen et al. 2011) in people with Parkinson’s disease.

Currently, the infrastructure of community set dancing classes for people with Parkinson’s disease is limited by inadequate knowledge and provision of information to lay community set dancing teachers. Set dancing teachers have called for appropriate guidance to enable them to teach enjoyable and safe classes to people with Parkinson’s disease in their local communities (Shanahan et al. 2016b). An inadequate number of community exercise programmes can compromise activity levels in those with Parkinson’s disease (Hirsch 2009). In turn, this may worsen gait and everyday functioning (van Nimwegen et al. 2011) leading to further inactivity, muscle weakness (Duncan and Earhart 2011, Speelman et al. 2011, Wallén et al. 2015), depression (Frisina et al. 2008), social isolation (Soleimani et al. 2014, Soundy et al. 2014) and fear of falling (Lindholm et al. 2014). It is apparent that education and research dissemination are needed to bridge the gap between academia and communities and facilitate the availability of community set dancing classes for people with Parkinson’s disease. Community health education is advocated to encourage healthy lifestyles (Nutbeam 2000) and may be a useful endeavour to facilitate physical activity participation in conjunction to translating research into community practices. This chapter describes the methods used to develop an educational resource to guide the lay community set dancing teachers when delivering classes to people with Parkinson’s disease. Significantly, the methods presented are innovative, contemporary and evidence-based and may be influential for promoting community research translation in other forms of dance and exercise and increase community health literacy.

### 6.2 Methods

The development of the educational resource was informed by the CDC recommendations for the creation of health communication materials (brochures,
booklets, web-based material) (Centre for Disease Control and Prevention 2009). These recommendations provide a systematic approach for creating evidence-based and user relevant and friendly material. Specifically, the methodological design for developing the educational resource involved four phases, which provided an overarching framework for applying the seven steps of CDC recommendations and the pillars of evidence-based practice. The pillars of evidence-based practice involve research evidence, patient values and preferences, practice expertise, and context (Jacobs et al. 2012). Thus, the educational resource may optimise the success of community set dancing classes for people with Parkinson’s disease by contextualising evidence and the needs of people with Parkinson’s disease and educational guidance sought by set dancing teachers within the development framework (Jacobs et al. 2012).

The following section presents the methods used in each of the four developmental phases of the educational resource. A summary flow diagram of the four phases of the research is presented in Figure 6.1. Community engagement, which was undertaken during Phase 1, was a critical part of developing the educational resource. Community engagement enabled the needs of people with Parkinson’s disease and set dancing teachers to be identified and considered during the development of the educational resource. This ensured the educational resource was relevant and specific to facilitate safe and enjoyable set dancing classes for people with Parkinson’s disease. Community engagement may also create a sense of ownership and maximise the success of public health activities such as set dancing in the community (Hirsch et al. 2011, Jacobs et al. 2012). Due to the importance of this community engagement phase in the development of the educational resource, an in-depth discussion of the methods used as well the results is justified. Therefore, the following section only introduces the methods used in Phase 1. A more comprehensive discussion of Phase 1 is presented in Chapter 7. Consequently, the remainder of this chapter will focus more on methods used in Phase 2 to 4.
Figure 6.1 Summary Diagram of the Developmental Process of the Educational Resource

**CDC Step 1: Identify need for material**
*Set dancing teachers identified the need for this resource at a conference in Feakle in November 2013*

**Phase 1**
Group discussions with:
- People with PD
- Set dance teachers

**CDC Step 2 and 3**
Engage audience, identify key gaps in knowledge

**Phase 2**
Draft resource using:
- Evidence
- Phase 1 results

**Phase 3**
- Expert review
- Re-draft resource
- Distribute resource to participants

**Phase 4**
- Edit resource
- Publication

**CDC Step 4**
Design draft

**CDC Step 5**
Pre-test material on intended audience

**Phase 4**
- Edit resource
- Publication

**Context**
- Experience
- Patient preference
- Evidence

**Educational resource**

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6.2.1 Phase 1 (practitioner expertise and patient preferences)

This phase involved community engagement in which two consensus group discussions, using nominal group technique (Pottter et al. 2004, Kleiner-Fisman et al. 2013) were held with five set dancing teachers and six people with Parkinson’s disease. As discussed above, an in-depth discussion of the methods and results of this phase is presented in Chapter 7.

6.2.2 Phase 2 (research evidence and context)

In this phase the findings from the group discussions held in Phase 1 and evidence-based information were contextualised to create a draft version of the educational resource. Research evidence informed the draft version as follows:

1) **The findings of the group discussions conducted in Phase 1:**

The results of the nominal group discussions were used to inform the topic areas to be covered in the educational resource. The results also informed the specific content and development of key considerations for set dancing classes for people with Parkinson’s disease and identified precise information that needed to be included on the symptoms of Parkinson’s disease and their effect on set dancing performance.

2) **The results of the systematic review, feasibility study and pilot RCT described earlier in this thesis:**

The results of these projects were used to inform content on the benefits of set dancing, safety precautions for teaching set dancing to people with Parkinson’s disease and potential effects of Parkinson symptoms on set dancing performance. The findings of this project also provided key considerations for set dancing classes for people with Parkinson’s disease including warm-up exercises, teaching strategies, class scheduling and the importance of creating an enjoyable atmosphere.
3) The results of other research in the area of set dancing for people with Parkinson’s disease

Additional studies that examined the positive effects of set dancing for people with Parkinson’s disease also informed the educational resource (Volpe et al. 2013, Brogan 2015, Flynn 2015). Specifically, two qualitative studies, that were carried out as a follow-up to this project, provided rich information on the perceived benefits of set dancing for people with Parkinson’s disease and caregivers. The results of Volpe et al. (2013) also provided information to inform content on the benefits of set dancing in the educational resource.

4) Broader published literature on the symptoms and pathology of Parkinson’s disease, first aid guidelines as well as literature in the area of dance and exercise for people with Parkinson's disease. Research in the broader context of dance and exercise was also considered if appropriate and transferable to people with Parkinson’s disease.

Evidence-based information on the symptoms and pathology of Parkinson’s disease was contextualised to inform the educational needs of set dancing teachers and the development of safety guidelines for set dancing classes for people with Parkinson’s disease. First aid guidelines were incorporated into the educational resource to ensure teachers have an awareness of the safety procedures to follow in the event of an incident. Research in the area of dance and exercise informed the content on key considerations for a set dancing class for people with Parkinson’s disease including safety precautions, teaching advice for teachers and class structure.

6.2.3 Phase 3 (peer-review, practice expertise and context)

The first part of this phase involved peer-review. Peer-review is an important tool to ensure the quality and validity of evidence-based research and resources (Voight and Hoogenboom 2012).
Four reviewers (who were part of the research team) independently reviewed the educational resource and provided electronic feedback. Reviewers did not engage with one another during the review process and had knowledge of the literature on dance for Parkinson’s disease. Two reviewers had clinical and research expertise in Parkinson’s disease and experience in delivering set dancing classes to people with Parkinson’s disease. The third reviewer had expert knowledge on set dancing and cultural dance genres. The fourth reviewer had clinical expertise in physiotherapy, intervention design and research methods.

To ensure the reviewers critiqued the resource in line with the aim, they were asked to focus their review on the following question:

“In your expert opinion, what do set dancing teachers need to know about Parkinson’s disease in order to deliver safe, feasible and effective set dancing classes for this population?”

All reviewers provided electronic feedback and the educational resource was re-drafted in line with review comments. The revised educational resource was sent back to two reviewers to ensure they were satisfied with the modifications made. These two reviewers reviewed the educational resource twice as further modifications were suggested.

The second part of this phase involved distribution of the educational resource, via email, to two set dancing teachers and two individuals with Parkinson’s disease who participated in the group discussions held during Phase 1. This was done to ensure the resource was relevant, easy to understand and met their needs. The individuals that provided feedback on the draft resource were randomly selected from the sample of set dancing teachers and people with Parkinson’s disease that participated in the group discussions. Random selection was done by selecting the names of two set dancing teachers and individuals with Parkinson’s disease from a hat.
6.3.4 Phase 4

This phase involved editing the resource in line with feedback of the set dancing teachers and publishing the final version. The final version of the educational resource is presented in Appendix A.

6.3 Epilogue

This chapter described the methodological procedures used to develop an educational resource for set dancing teachers. This educational resource will be used to inform set dancing teachers about Parkinson’s disease and to facilitate lay community set dancing teachers to teach set dancing to those with Parkinson’s diseases.

The educational resource considers the pillars of evidence-based practice (Jacobs et al. 2012) and will therefore, facilitate the dissemination and translation of the findings of this research at a community level. This will have direct impact on the quality of set dancing classes for community-dwelling individuals with Parkinson’s disease. Disseminating research through the educational resource will also create community awareness of Parkinson’s disease. For people with Parkinson’s disease, this may positively impact their everyday lives and help increase social confidence and self-esteem (Soundy et al. 2014).

An important part of evidence-based practice is identifying the needs and preferences of patients. The educational resource considers the needs of people with Parkinson’s disease from a set dancing class. This will ensure that dancing classes are person-centred. This may improve satisfaction and attendance (Grosset and Grosset 2005). The consideration given to both the needs of set dancing teachers and people with Parkinson’s disease also ensures that the resource is relevant and useful within the context of community set dancing classes for people with Parkinson’s disease.
Chapter 7

Irish set dancing classes for people with Parkinson's disease: the needs of participants and dance teachers

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

Narrative review  Systematic review

Feasibility study

Pilot RCT

Dissemination
7.0 Prologue

Chapter 7 presents a study that informed the first developmental phase of the educational resource. This study expands on the overview of Phase 1 provided in chapter 6. The aim of this study was to examine (1) the needs of people with Parkinson’s disease from a set dancing class and (2) the educational requirements of experienced set dancing teachers in order to teach set dancing to those with Parkinson’s disease. The information gathered in this study will be used to inform the development of an educational resource that is context-specific and relevant to those with Parkinson’s disease and set dancing teachers. Therefore, the results will facilitate evidence-based participant-centred community set dance classes. The research article based on this study was published in Complementary Therapies in Medicine (Shanahan et al. 2016b).

7.1 Introduction

Parkinson's disease is a progressive condition associated with functional disability (Tan et al. 2012), social isolation and reduced quality of life (Chiong-Rivero et al. 2011). Promoting regular participation in physical activity is one initiative recommended in the management of Parkinson's disease (Keus et al. 2014). Regular participation in physical activity may prevent secondary consequences of sedentary lifestyles (Speelman et al. 2011), increase functional ability (Borrione et al. 2014), improve quality of life (Ellis and Motl 2013) and reduce referral into the health system (Hirsch et al. 2011). Unfortunately, the level of engagement in habitual physical activity is poor for those with Parkinson's disease as approximately 64% of this population are leading sedentary lifestyles (Hirsch et al. 2011). Lack of suitable service provision (Hirsch 2009), low expectation and interest in the activities offered and low self-efficacy (Ellis et al. 2011, Ellis et al. 2013) have been identified as barriers to exercise by people with Parkinson's disease. Physical limitations including postural instability and gait impairments may also deter exercise participation (van Nimwegen et al. 2011). Enjoyable exercise interventions that
Irish set dancing along with Tango (Lötzke et al. 2015) and different forms of modern dance (Batson 2010, Hashimoto et al. 2015) may be beneficial activities and encourage habitual participation in exercise in people with Parkinson’s disease. Irish set dancing is a social and partnered form of cultural dance and may improve balance, mobility and quality of life (Volpe et al. 2013, Shanahan et al. 2015a) through the integration of complex motor skill learning patterns, dynamic balance practice (Murphy 2000), musical cueing and socialisation (Foley 2011). Moreover Irish dance music has a predictable rhythmic beat which may improve the pattern of gait (Nombela et al. 2013). Irish set dancing is popular worldwide and practiced in America, Australia and Europe (Murphy 2009, O'Connor 2013). Preliminary research suggests Irish set dancing may have some therapeutic benefits in Irish and Venetian people with Parkinson's disease (Volpe et al. 2013, Shanahan et al. 2015a).

In 2013, a national conference, "Training course for Irish set dancing teachers and therapists: focusing on Parkinson's disease" was held. The aim of this conference was to provide preliminary information about teaching set dancing to people with Parkinson's disease to lay community, set dancing teachers and health care professionals. The conference provided symposium and workshop sessions, delivered by researchers, consultant neurologists and chartered physiotherapists with expertise in set dance and/ or Parkinson's disease. During this conference set dancing teachers noted that insufficient information was available to help them implement safe and beneficial set dancing classes for people with Parkinson's disease.

To the authors’ knowledge, no guidelines or resources exist to provide set dancing teachers with comprehensive information about teaching set dancing to people with Parkinson’s disease. The aim of this study is to identify the (1) educational needs of set dancing teachers and (2) elements required by people with Parkinson’s disease from a set dancing class. The information gathered will inform development of an educational resource that will address specific needs of set dancing teachers and guide delivery of client-centred set dancing classes for people with Parkinson’s disease in the community. Providing relevant information and educating set dancing
teachers may be one meaningful and novel initiative to help combat the lack of suitable community dance and exercise programmes for people with Parkinson’s disease, aforementioned. Educating set dancing teachers may also help establish supportive networks for people with Parkinson’s disease as community peers work together to achieve common goals.

7.2 Methods

7.2.1 Design

This project was approved by the Education and Health Sciences Ethics Committee. The methodology for this study was developed in line with previous research (Potter et al. 2004, Kleiner-Fisman et al. 2013).

Two separate consensus group discussions, one with set dancing teachers and one with people with Parkinson’s disease were conducted. Both group discussions used a nominal group technique (Potter et al. 2004, Kleiner-Fisman et al. 2013). This method allows for priority information in relation to a specific topic to be identified and prioritised through structured group discussion. Nominal group technique is more suitable than other qualitative methods such as focus groups when the aim of the discussion is to identify priority information in relation to a particular issue (Potter et al. 2004). Thus, nominal group technique was chosen for this study as it facilitated a structured group discussion in relation to the educational resource and enabled the most useful and relevant information for inclusion in the resource to be identified. A nominal group technique also gives each participant an equal opportunity to speak and prevents individuals from dominating the discussion (Potter et al. 2004, Kleiner-Fisman et al. 2013).

The aim of the discussion with set dancing teachers was to identify their educational requirements in order to teach set dancing to people with Parkinson's disease. For those with Parkinson’s disease, the group discussion focused on identifying their needs for the structure of a set dancing class and the knowledge they would like set dancing teachers to have about Parkinson’s disease. The consensus group
discussions were held on a suitable day and time, in a location convenient to participants. A chairperson (J.S.) was present at both group discussions. All data collected was anonymised. Each group discussion began with a brief introduction to the session and silent generation of individual ideas. Following this, a round-robin sharing of ideas took place. In this part of the discussion, participants called out one item from their individual list of ideas. The chairperson wrote down all ideas shared on a full view flip chart and ensured each participant was given an opportunity to speak. The process of round-robin sharing continued until participants had shared all items on their lists. Participants then discussed all the items on the flip chart and with the help of the chairperson, related items were compiled, via group consensus, to create broader topic areas that represented similar factors pertinent to their needs. Finally, participants were asked to privately rank, by order of priority (Pottter et al. 2004, Kleiner-Fisman et al. 2013), (1-5: 1 least important, 5 most important) the topic areas developed during the round-robin discussion.

### 7.2.2 Selection of participants

Set dancing teachers, were recruited by an email invitation. This invitation was sent via a gatekeeper, to set dancing teachers on a national database of set dancing teachers for people with Parkinson's disease. Those with Parkinson’s disease were recruited by a postal invitation, distributed to people who participated in a study exploring the benefit of set dancing for people with Parkinson’s disease (Shanahan et al. 2013). This was done to ensure participants would have experience of set dancing and thus be able to contribute participant evidence to the study. All participants received a patient information leaflet (Appendix N and Appendix O) and were required to provide written informed consent (Appendix P) prior to participating in the study. Participants were also asked to provide an email address so a draft version of the resource could be emailed for review and feedback.
7.2.3 Data analysis for consensus group discussions

Demographic information for set dancing teachers was collected and presented descriptively. Descriptive statistics using SPSS version 22 were used to analyse demographic information for those with Parkinson’s disease.

The final data collected from the group discussions was analysed by tabulating participants rank-ordering of items to be included in the educational resource. The most important item received the highest ranking score-(5) (Pottter et al. 2004). Participants’ top five ranking items were included in the educational booklet. This ensured in-depth information was provided on the topics identified as most relevant.

7.3 Results

7.3.1 Description of participants

Five set dancing teachers volunteered to participate. All participants taught set dancing in the community and had been involved in classes for people with Parkinson's disease. Participants had limited knowledge of the evidence-based information available in the area of dance for people with Parkinson's disease.

Six people with Parkinson's disease participated in the study. The demographic profile of participants is presented in Table 7.1.

Table 7.1 Demographic Characteristics of participants with Parkinson’s disease

<table>
<thead>
<tr>
<th>Demographic Characteristic (n=6)</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>70.5±8.5 (66, 79)</td>
</tr>
<tr>
<td>Modified Hoeln and Yahr</td>
<td>2±1.13 (1, 2.5)</td>
</tr>
<tr>
<td>Gender (male/female)</td>
<td>4:2</td>
</tr>
<tr>
<td>Duration of disease (years)</td>
<td>9.5±13.75 (2, 18)</td>
</tr>
<tr>
<td>UPDRS-3</td>
<td>13.5±12.5 (7, 39)</td>
</tr>
</tbody>
</table>

Values are median± interquartile range (minimum, maximum values), UPDRS-3=unified Parkinson’s disease rating scale subsection-3
7.3.2 Findings

Figure 7.1 and Figure 7.2 display a summary of the topic areas participants felt most important to include in this resource and the ranking results. The topic area that received the highest ranking score was deemed most relevant to participants. Topic areas with the same ranking score were deemed as having equal importance.

Within each topic area, suggested factors and/or items for discussion in the educational resource were developed. These items were generated during the round-robin sharing of ideas and are presented in Table 7.2 and Table 7.3.

**Figure 7.1 Topic Areas Selected by People with Parkinson's Disease**

<table>
<thead>
<tr>
<th>Topics</th>
<th>Sum of ranking score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teaching method</td>
<td>30</td>
</tr>
<tr>
<td>Environment</td>
<td>20</td>
</tr>
<tr>
<td>Inclusion of a warm-up</td>
<td>15</td>
</tr>
<tr>
<td>Experienced dancers at class</td>
<td>10</td>
</tr>
<tr>
<td>Teachers understanding of Parkinson's disease</td>
<td>5</td>
</tr>
</tbody>
</table>

Numbers presented are sum of participant’s ranks. Highest score represents most relevant topic. 30 was the highest achievable score.
Figure 7.2 Topic Areas Selected by Set Dancing Teachers

![Bar Chart]

Numbers presented are sum of participant’s ranks. Highest score represents most relevant topic. 25 was the highest achievable score.
<table>
<thead>
<tr>
<th>Topic area</th>
<th>Associated items for discussion</th>
</tr>
</thead>
</table>
| **Teaching method**           | • Teacher should be familiar with all dancers past dancing experience  
• Steps and movements must be simplified into individual elements  
• Progress complexity of material in line with dancers ability  
• Never lose patience if some individuals are having difficulty learning steps/movements  
• Make all dancers feel “welcome” by modifying usual teaching method/ movements to each individual’s ability |
| **Environment**               | • Teacher should create a relaxed atmosphere  
• Teacher should let conversation and friendships develop  
• Dancing class should be a pleasure to attend and dancers want to look forward to it  
• Teacher should not be strict and rigid when it comes to perfection of sets |
| **Inclusion of warm-up**      | • Warm-up helps one “to get going” and moving  
• Needs to be enjoyable and exercises should be specific for people with Parkinson’s disease  
• Progression and new exercises increase motivation but complex exercises should be avoided |
| **Experienced dancers at class** | • Helps with learning steps/ movements through observation  
• Provides support  
• Provides motivation to learn set dancing  
• Nice to meet new people and mix with a wider social group |
| **Teachers understanding of Parkinson’s disease** | • Teachers understanding is connected to the teaching methods they will use  
• Teachers knowledge of Parkinson’s disease must be used to inform their teaching methods  
• Teachers should understand the individuality of symptoms associated with Parkinson’s’ disease and the different barriers they might have to overcome to help a dancer learn what is been taught  
• Teachers should understand that an individual’s severity of Parkinson’s disease may affect their ability to complete certain movements/steps. (Teachers should be able to modify in order to help these individuals achieve and learn)  
• Teachers should understand that practice is the key to motor learning for people with Parkinson’s’ disease  
• An individual’s age should also be considered when devising a teaching plan |
Table 7.3 Topic Areas and Associated Factors and/or Items Relevant to Set Dancing Teachers

<table>
<thead>
<tr>
<th>Topic area</th>
<th>Associated items for discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is Parkinson's disease</td>
<td>• Pathology</td>
</tr>
<tr>
<td></td>
<td>• Symptoms</td>
</tr>
<tr>
<td></td>
<td>• Different stages of disease and how to recognize those with different stage of disease</td>
</tr>
<tr>
<td></td>
<td>• How dancing helps people with Parkinson's disease</td>
</tr>
<tr>
<td>Class guidelines specifically for teaching set</td>
<td>• List of set dancing movements that are most beneficial</td>
</tr>
<tr>
<td>dances to people with Parkinson’s disease</td>
<td>• Suggested methods for teaching set dancing steps and movements</td>
</tr>
<tr>
<td>Teachers pre-class preparation</td>
<td>• Methods to adjust class material to suit varying degrees of ability</td>
</tr>
<tr>
<td></td>
<td>• Suggestions toward communicating benefits of exercise and dance to people with Parkinson's disease to promote participation</td>
</tr>
<tr>
<td></td>
<td>• Tips on how to ascertain if an individual is suitable based on observational assessment</td>
</tr>
<tr>
<td></td>
<td>• Method for participants to identify improvements e.g. self-administered questionnaire of health/quality of life</td>
</tr>
<tr>
<td></td>
<td>• Class scheduling required for benefit e.g. number of recommended sessions or weeks to run dance classes, suitable class times</td>
</tr>
<tr>
<td>Warm-up exercises</td>
<td>• A comprehensive list of exercises suitable for all stages of disease and progression ideas</td>
</tr>
<tr>
<td></td>
<td>• Recommended warm-up time</td>
</tr>
<tr>
<td>Safety advice</td>
<td>• Strategies to help manage symptoms while dancing e.g. ways to overcome freezing of gait</td>
</tr>
<tr>
<td></td>
<td>• Description of set movements/exercises that may be problematic for people with Parkinson's disease</td>
</tr>
<tr>
<td></td>
<td>• Suggestions for communicating with individuals who you feel may be unsuitable for set dancing</td>
</tr>
</tbody>
</table>
7.4 Discussion

7.4.1 Findings in context

For people with Parkinson's disease, participation in many daily and social activities as well as exercise and hobbies can be negatively affected by motor and non-motor impairments (Schrag et al. 2000a, van Nimwegen et al. 2011, Ellis et al. 2013, Kluger et al. 2014). Community participation in exercise has been advocated to increase quality of life and socialisation. Notably, community involvement for this population may be difficult due to mobility limitations, poor balance, falls or lack of community infrastructure with respect to suitable amenities and services (Hirsch 2009, Hirsch et al. 2011, Merali et al. 2015). To the authors' knowledge, factors important to the delivery of community led dance classes for people with Parkinson's disease are not known. As such, this study determined the needs of people with Parkinson's disease and lay community set dancing teachers in order to inform an educational resource and aid development of a community set dancing infrastructure for people with Parkinson's disease. The results show participants have multidimensional needs with respect to dance including personal, environmental, physical and knowledge-based factors. The identification of these needs will help to better understand participants’ requirements from a dance class and ensure development of a participant-centred educational resource and dance classes. While this study focused specifically on set dancing, many of the factors identified are pertinent for delivering satisfactory classes in other dance genres and may be used by researchers or dance professionals involved in multiple community or rehabilitation dance programmes.

The results show that set dancing teachers require more information on the pathology of Parkinson’s disease, the symptoms associated with the condition and the effect symptoms may have for learning and performing set dancing. This is an important finding as it shows the need for researchers and health professionals to engage, educate and empower community members to use their skills and develop dance programmes for people with Parkinson's disease. Researchers and clinicians should consider the potential role of community-healthcare partnerships (Hirsch et al. 2011,
Merali et al. (2015), whereby health professionals or researchers train or provide educational resources to community experts to deliver community dance and exercise programmes for people with Parkinson's disease. This approach may improve service availability, encourage community involvement, broaden social networks and increase community knowledge so that dance and exercise programmes pertaining to the needs of those with Parkinson's disease are made available. Providing adequate knowledge and awareness will enable community experts such as set dancing teachers to make informed decisions regarding appropriate dance material for those with Parkinson's disease or readily modify dances to suit physical capacities, prevent falls and acknowledge the needs of each individual.

Until now, little was known about environmental factors pertaining to the needs of people with Parkinson's disease from a dance class. The findings of this study suggest people with Parkinson's disease are very concerned with the social and emotional environment of dance classes. People with Parkinson's disease ranked environmental factors higher than the disease-specific knowledge of set dancing teachers (Figure 7.1). However, this may indicate desires for dance classes that focus on enjoyment rather than disease related issues. In this way, dance classes may help reduce anxiety (Blum and Lesch 2015) and fears about social interaction in people with Parkinson's disease (Hirsch et al. 2011). Kleiner-Fisman et al. (2013) also found people with Parkinson’s disease had greater emotional and social needs in relation to factors affecting quality of life than disease-specific parameters. Therefore, to create participant-centred dance classes, researchers, dance instructors and health professionals should identify strategies to optimise participants’ social experience and emotional satisfaction. The class environment appears to be particularly important as Allen and Morey (Allen and Morey 2010) found higher levels of adherence were reported in exercise programmes fostering a sense of social cohesion and support. Socially stimulating environments may increase neuroplasticity (Kattenstroth et al. 2010) as well as serotonin (Young 2007, Kiser et al. 2012) which is implicated in fatigue and other non-motor symptoms associated with Parkinson’s disease (Blonder and Slevin 2011, Politis and Niccolini 2015). Furthermore, the cultural context of Irish set dancing may enhance these qualitative
aspects as common cultural interests and identities can foster a sense of togetherness and friendships (Foley 2001, Kavanagh et al. 2008). For non-Irish populations, knowledge of the cultural heritage associated with set dancing may stimulate nostalgia and conversation with respect to their native traditions and create a sense of common understanding, safety and aid development of social networks.

Although, people with Parkinson’s disease in this study were concerned with the social and emotional environment of dance classes, they did not identify the physical dance space as an important issue. While this may seem surprising, participants had taking part in the pilot RCT described in Chapter 5 of this thesis and dance halls with appropriate flooring and facilitates were chosen. It is important that dance teachers consider the appropriateness of the dance space as this will impact on dancers’ perceptions of safety and enjoyment. For example, dance halls with slippery floors may increase fear of falling and deter participation. Equally, a dance hall with good acoustics is essential and may influence dancers’ perceptions of the music and thus, enjoyment. Future studies may consider exploring the influence of the dance hall on sense of enjoyment and motivation to continue participation.

Notably, this study shows the degree to which set dancing teachers and people with Parkinson’s disease concur about teaching methods. In particular, participants were concerned with the aspect of breaking down dance steps and movements. The use of appropriate teaching methods in dance is very important to reduce falls risk, prevent festinating and freezing of gait, facilitate movement and enhance motor skill learning (Morris 2000). It is also important for those involved in dance interventions to know which aspects of dance may exacerbate these movement difficulties aforementioned and understand the teaching strategies that may minimize their occurrence. Research has shown movement strategy training can be used to facilitate motor learning and correct execution of movements (Rochester et al. 2013). Notably, the suggestion from participants to “break down movements” is comparable with the principles of movement-strategy training and thus may be one approach for teaching set dancing and other dance forms to people with Parkinson’s disease. Additionally, the use of music in set dancing may act as an external cue and facilitate movement by entraining motor output to the rhythmic beat of Irish music (Nombela et al. 2013).
Music may have positive implications for symptoms of depression in people with Parkinson’s disease as it activates the mesolimbic-striatum network (Zatorre and Salimpoor 2013) and the amygdala, that is the neural substrate where emotional reactions to music are processed (Xueting Li et al. 2014).

7.4.2 Wider implications and transferability

In this study the authors sought to establish the needs of people with Parkinson’s disease and set dancing teachers in order to inform the content of an educational resource for set dancing teachers. This may enable development of community set dancing classes for people with Parkinson’s disease and help prevent secondary consequences of physical inactivity (Speelman et al. 2011). With acknowledgment of the recognised link between physical activity and health in those with chronic diseases (Stewart et al. 1994, Durstine et al. 2013, Borrione et al. 2014), future studies may use similar approaches in order to develop the infrastructure of safe and sustainable community dance and exercise programmes for people with Parkinson’s disease. Involving both service users and providers in the development of the current educational resource was necessary to enhance relevance, value and usability and may be an important methodological consideration for future studies developing health communication material (Centre for Disease Control and Prevention 2009). Exploring the needs of set dancing teachers will ensure appropriate information is available to help facilitate safe and beneficial dance classes. Conversely, informing set dancing teachers of the needs and opinions of people with Parkinson’s disease is equally important to foster long-term participation and satisfaction in set dancing. Ultimately, this may reduce reliance on the health system and promote health and wellbeing through the neuro-protective effect of exercise (Hirsch et al. 2011).

A limitation of this study is the small sample size. However, a low number of participants in each group was preferable to allow in-depth exploration of topics and encourage active involvement from all participants (Kleiner-Fisman et al. 2013).
7.5 Conclusion

Community physical activity programmes are important in the self-management of Parkinson’s disease. Unfortunately, access to resources or the availability of community physical activity programmes for those with Parkinson’s disease can be limited. This paper examined the needs of people with Parkinson’s disease and set dancing teachers in relation to set dancing. The inclusion of service users and providers in this study will allow the needs of both groups to be represented in an educational resource that aims to guide set dancing teachers delivering set dancing classes to people with Parkinson’s disease. This approach may help sustain interest, enjoyment and motivation in set dancing. Furthermore, this study enables the provision of guidelines to enhance the experience of those engaging with set dancing for Parkinson’s.

7.6 Epilogue

This chapter accomplished its aim to examine (1) the needs of people with Parkinson’s disease when participating in Irish set dancing classes and (2) the educational needs of set dancing teachers when teaching set dancing to people with Parkinson’s disease. The findings identified key information pertinent to the successful delivery of community set dancing classes for those with Parkinson’s disease. Topic areas developed during the group discussions include “teaching method” for set dances, “understanding of Parkinson’s disease” and “class environment”. These finding will be used to inform Phase 2 of the development of the educational resource which was previously described in Chapter 6.

The use of consensus group discussions involving nominal group technique was an important aspect of the methodology used in this study and enabled the identification of priority information to be discussed in the educational resource. By focusing on topics most relevant to participants, the educational resource will comprehensively address the preferences of participants from a dance class and educational guidance sought by set dancing teachers. Consequently, the use of the educational resource
may facilitate a larger number of suitable, safe and enjoyable dance classes in local communities for people with Parkinson’s disease.

These results of this study also show that participants with Parkinson’s disease have multidimensional needs in relation to set dancing and suggest a holistic approach is needed to facilitate participation and enjoyment. Researchers, clinicians and dance instructors may consider these findings when developing and delivering participant-centered classes in other dance genres.
Chapter 8

Discussion and Conclusion

Is Irish set dancing feasible and beneficial for people with Parkinson's disease in Ireland?

Narrative review

Systematic review

Feasibility study

Pilot RCT

Dissemination
8.0 Introduction

The aim of the research project undertaken was to inform the research question-Is Irish set dancing feasible and beneficial for people with Parkinson’s disease in Ireland? and to disseminate the findings of the research. It is evident from the work presented that each stage of this project had a unique purpose, informed the research question and provided both novel and valuable information to facilitate subsequent stages of the research process.

The following section will discuss the impact of the key research findings and the implications for practice and future research.

8.1 Impact of Findings to Practice and Research

8.1.1 Findings in the context of the broader literature

The results of the feasibility study and pilot RCT found that set dancing is motivating and enjoyable and showed some improvement in quality of life. The music in set dancing, along with the social and cultural context, may benefit quality of life by encouraging conversation, laughter and stimulating neurotransmitters such as dopamine and serotonin (Evers and Suhr 2000, Foley 2011, Cuypers et al. 2012, Altenmüller and Schlaug 2013, Hackney and Bennett 2014). These neurotransmitters are involved in emotional regulation and sensations of reward and pleasures (Altenmüller and Schlaug 2013). Thus, set dancing may afford a satisfying exercise experience and encourage long-term participation (Thomas 2001). This is in agreement with other studies in older adults that found cultural participation was associated with greater life satisfaction (Cuypers et al. 2012) and retention of physical activity levels over a 12 month period (Cohen et al. 2006). This project is also part of a growing body of literature that indicates music, song, cultural programmes and dance can afford health benefits (Cohen et al. 2006, McNeely et al. 2015a, Raglio et al. 2015b, Reagon et al. 2016). Arts practices offer a holistic option for improving health and wellbeing (Staricoff 2004, Staricoff and Clift 2011, Wilson et al. 2016). Music based interventions have been shown to improve mood,
depressive symptoms and anxiety in some patients with neurological conditions
(Raglio et al. 2015b). The addition of music to rehabilitation therapies including
cardiac and pulmonary rehabilitation may also have positive effects on perceived
rate of excretion in those with Chronic Obstructive Pulmonary Disease (COPD) and
improve exercise capacity and motivation levels in those with cardiac disease and
COPD (Ziv and Lidor 2011). Furthermore, listening to music and active music
making have also been reported to enhance social and emotional well-being (Creech
et al. 2013) in older adults. This project also identified that research evaluating the
effect of set dancing on mood are warranted. In other studies, social dance was
reported to improve mood (Lewis et al. 2014). Positive effects on depression
(Blandy et al. 2015, Hashimoto et al. 2015), as well as fatigue (Rios-Romenets et al.
2015) were also reported following Tango programmes. However, further research is
needed to confirm the benefits of various dance genres on non-motor symptoms in
those with Parkinson’s disease (McNeely et al. 2015b). Therefore, it is
recommended that future studies examine the effect of set dancing on a range of
outcomes including mood and fatigue and social isolation in those with Parkinson’s
disease as well as older adults.

This research project is in line with recommendations of national and international
reports that recognised the potential health benefits of dance participation
Dance offers a meaningful way to connect with others, experience emotions and
foster enjoyment, personal expression and satisfaction; all of which may drive
continued participation (Houston and McGill 2013, Dhami et al. 2015, Maraz et al.
2015). Evidence suggests dance may prevent functional deterioration in nursing
home residents with and without cognitive impairment (Machacova et al. 2015),
improve concentration and communication with others in older adults with dementia
(Hamill et al. 2011) and improve spatial memory in older adults without cognitive
impairment (Merom et al. 2016b). Previous studies have identified that Tango may
improve cognition (Hashimoto et al. 2015). Cognition was not assessed as part of
this research project; as the focus was to assess the benefits for motor function,
quality of life, balance and endurance. The combination of cognitive and physical
exercise in set dancing justifies the need to explore the effects of set dance on
cognition in those with Parkinson’s disease. Notably, the combination of cognitive and physical exercise in set dancing also emphasizes the need to examine the benefits of set dancing for those with dementia (Yoon et al. 2013). Additionally, research has shown dance can afford social benefits in healthy community-dwelling adults and older adults with dementia (Hamill et al. 2011, Lakes et al. 2016). As set dancing is a social dance genre (Foley 2011) it is recommended that future studies also investigate the social benefits of set dancing for people with Parkinson’s disease as well as older adults with and without dementia.

Dancing at moderate intensities is associated with a reduced risk of cardiovascular disease mortality in middle aged adults (Merom et al. 2016a). For people with neurological conditions such as Parkinson’s disease, dance combines important rehabilitation components including balance training, aerobic exercise, external cueing and transition between dynamic movement patterns (Earhart 2009). Therefore, set dancing participation may help to prevent secondary consequences of inactivity such as cardiovascular disease and osteoporosis and slow the progression of postural instability (Speelman et al. 2011). While this project did not report improvements in aerobic capacity or balance after the set dancing programme, previous research in older adults found that regular set dancing participation for a minimum of six months is associated with better balance, endurance and quality of life compared to age-matched controls (Shanahan et al. 2016a). Therefore, longer duration studies that allow more time for the exercise intensity and complexity of dance material to progress are warranted in those with Parkinson’s disease.

8.1.2 Impact on Research

The potential impact of set dancing on caregivers led to a qualitative study by Brogan (2015). This study used focus groups to examine the experiences of set dancing in those that care for people with Parkinson’s disease. Currently, there is a lack of research investigating the benefits of dance for caregivers, despite their class participation (Aguiar and Morris 2016). Therefore, the study by Brogan (2015) helps to inform this gap in the literature. Also, caregivers can experience burden, mood conditions and reduced quality of life (Martinez-Martin et al. 2008, Martinez-Martin
et al. 2015) and it is important to examine if set dancing can help carers to cope better. The results of the study by Brogan (2015) show that caregivers perceive many benefits from set dancing including personal satisfaction, social interaction, psychological support and physical benefits for their partner and their own health. Thus, these results emphasise the importance of inviting caregivers to set dancing for people with Parkinson’s disease. It is recommended that future studies also examine the benefits of set dancing and other dance forms for caregivers using qualitative and quantitative methods.

8.1.3 Research translation

The development of the educational resource is another original aspect of this project and provides extensive scope for implementing the findings into practice. The educational resource will guide set dancing teachers and facilitate the availability of more local classes for people with Parkinson’s disease. Set dancing classes for people with Parkinson’s disease can be easily integrated into community activities as many urban and rural areas of Ireland have local teachers. The community context of the research undertaken increases the appropriateness of the educational resource to enhance the quality of community classes for individuals with Parkinson’s disease. The needs of set dancing teachers and people with Parkinson’s disease were also considered during the development of the educational resource. This needs-based assessment was important to enhance the relevance of the resource to set dancing teachers and to facilitate participant-centred and sustainable community set dancing classes for individuals with Parkinson’s disease. The provision of classes that are specific for those with Parkinson’s disease may encourage habitual participation (Hirsch 2009, Hirsch et al. 2011) and target sedentary behaviours (Wallén et al. 2015). Notably, this novel method of disseminating research enhances the immediate and long-term practical impact of this project as set dancing teachers may use the resource to facilitate long-term set dancing classes for people with Parkinson’s disease.
8.1.4 Increased community awareness

The educational resource along with the voluntary participation of set dancers without Parkinson’s disease in the classes will also create community awareness and understanding of this condition. This may alleviate feelings of social stigma and improve confidence and self-esteem in those with Parkinson’s disease (Soundy et al. 2014). Furthermore, this is one of the first projects to identify the subjective needs of people with Parkinson’s disease from a dance class. Many of the needs identified are generalizable to other dance genres and may impact the quality of dance classes.

The involvement of multiple locations across the country in the pilot RCT is a strength of this project. It allowed a wider demographic representation of people with Parkinson's disease to participate in the research, thus increasing the generalisability of findings across the population. The involvement of multiple locations in the pilot RCT also had great impact at a community level and encouraged a number of Parkinson’s Support Groups and branches of the Parkinson’s Association of Ireland to establish set dancing classes for people with Parkinson’s disease. Each year the popularity of these classes has grown and there are now nine set dancing classes available for people with Parkinson’s disease in Ireland. The establishment of these classes allowed people uninvolved in the study to hear about set dancing and participate. This emphasises the impact of this project on many Irish people with Parkinson’s disease.

8.1.5 Impact for clinical practice

The establishment of local set dancing classes is also relevant for clinical practice as set dancing may be a suitable exercise hobby to complement usual care and target some of the disabling consequences of this condition (Schrag et al. 2000a, Cornwell and Waite 2009, Tan et al. 2012). Critically, the systematic review of the literature on dance for those with Parkinson’s disease will inform clinicians about an optimum dosage of dance for this population. This will help clinicians give appropriate advice to patients who consider dancing as an adjunctive exercise hobby.
8.1.6 Culture and social engagement

As indicated by the results of this project and Volpe et al. (2013), participation in set dancing may improve quality of life, motor function and mobility. The social aspect of set dancing may foster new friendships, encourage sharing of disease-specific information such as coping or movement strategies or inform people about other community activities. In turn, this may prevent social isolation (Cornwell and Waite 2009), improve participation levels (McGill et al. 2014) or empower self-management by enhancing coherence of Parkinson’s disease (Chenoweth et al. 2008) and facilitating informed decision making (Iansek and Morris 2013b). In an Irish context, set dancing is a cultural and social activity that centres around enjoyment and learning sets as opposed to focusing on the therapeutic implications of participation (O’Connor 2013). Therefore, set dancing may give people with Parkinson’s disease an opportunity to participate in a typical Irish activity and help to retain social identities and temporarily escape from their diagnoses of Parkinson’s (Soundy et al. 2014). The potential benefit of set dancing highlights the need for longer and larger international studies in those with Parkinson’s disease and other populations. Although, this study did not examine the social benefits of set dancing, a follow-up study by Flynn (2015) used focus groups to explore the experiences of set dancing in people with Parkinson’s disease. This study complemented the quantitative methods of the current project and showed the holistic benefits of set dancing (McGill et al. 2014). The results demonstrated that hope was a key aspect of three main themes: sense of freedom, social element and future.

8.1.7 International impact

The findings of this project have international significance. Currently, Volpe et al. (2013) is the only published study that investigated the feasibility and benefit of set dancing in a non-Irish population. However, set dancing is popular in many other European countries as well as in America and Australia (Murphy 2009, Foley 2011) and larger international studies are warranted to investigate the cross-cultural benefits of set dancing. The pilot RCT was the first to compare set dancing to usual care that involved medication treatment only. Thus, the results are very applicable
in countries where rehabilitation therapies such as physiotherapy and occupational therapy and not continuously provided to patients. The results of the pilot RCT provide novel and important findings to inform international studies. For example resolvable scheduling issues in relation to resources were identified and need to be pre-empted when planning the timeline of larger trials. As the feasibility of a randomised controlled study design is relevant to all trials, the results of the pilot RCT highlight important research considerations to inform the design and quality of literature in other dance genres and populations. The data collected in the pilot RCT may also be used in sample size calculations for larger trials.

Additionally, this project is impacting upon the strategic plans of the Parkinson’s Association UK as they are considering implementing a new pilot scheme offering set dancing to their members. This further signifies the international impact of this project and substantiates the need for further investigations in older adults and those with dementia.

8.2 Limitations

The limitations of the different stages of the research project were highlighted throughout the thesis. Some key limitations of the project were:

This project recruited participants with mild to moderate Parkinson’s disease, specifically stages 1-2.5 on the modified Hoeln and Yahr scale. This limits the generalisability of the findings to those with more severe Parkinson’s disease and identified an opportunity for further research.

The aim of this project was to investigate the feasibility and benefit of set dancing for people with Parkinson’s disease in Ireland. The cultural context of set dancing in Ireland, may limit the generalisability of the results to other nationalities. As previously discussed in this thesis, further international trials examining the benefit of set dancing across various populations are recommended. Also, this study did not assess the long-term impact of set dancing participation for those with Parkinson’s
disease. However, the results of this project suggest that further long-term research is warranted.

This project did not use qualitative methods; as the focus was to assess the effect of set dancing on quality of life, motor function, balance and endurance using quantitative methods. However, the findings of this project led to further research opportunities as Brogan (2015) and Flynn (2015) used focus groups to explore the experiences of set dancing in people with Parkinson’s disease and their caregivers. These qualitative studies were discussed earlier in this chapter.

The modest sample size may be considered a limitation if the aim was of this project was to investigate the effectiveness of set dancing for people with Parkinson’s disease. However, the sample recruited was adequate to achieve to aims of each stage of the research project in particular to examine the feasibility and safety of a newly developed community set dancing programme and to pilot the methods for a larger RCT.

**8.3 Further Research**

Directions for future research were highlighted throughout this thesis. Some of key areas that require further research are:

The findings of this project indicate that larger multi-centre international RCTs with longer durations and follow-ups are needed to determine the effectiveness of set dancing for people with Parkinson’s disease in comparison to usual care. Additionally, research comparing the effectiveness of set dancing to other forms of exercise that can be implemented in the community would enhance the literature in this area.

As discussed earlier in this thesis, literature is emerging on the potential benefits of dance on non-motor symptoms associated with Parkinson’s disease. Therefore, it is recommended that future studies assess the impact of set dancing on physical, emotional, social and cognitive health in those with Parkinson’s disease.
Furthermore, research should consider the potential impact of dance participation on multi-dimensional health outcomes in caregivers involved in the set dancing classes.

8.4 Conclusion

This thesis presented a research project that examined the feasibility and benefit of Irish set dancing for people with Parkinson’s disease in Ireland. Throughout the research process a number of novel and important findings were identified which showed the feasibility, safety and enjoyable aspect of set dancing for this population. The results of this project also suggest set dancing may have protective benefits for motor function and improve quality of life in those with Parkinson’s disease. It is apparent that this project is impacting the lives of people with Parkinson’s disease by inspiring the establishment of set dancing classes for people with Parkinson’s disease throughout Ireland and affording a positive exercise experience. Importantly, the educational resource for set dancing teachers will facilitate the long-term impact of this project. Finally, this project has led to the development of future research, thereby enhancing literature in this area and the availability of community physical activity options for people with Parkinson’s disease.
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Appendix A: Educational Resource for Irish Set Dancing Teachers

“Set dancing...it gets into your feet, mind and body”
Purpose of booklet

This booklet, version 1 (2016), was created to provide a rich source of information to support teaching set dancing to people with Parkinson’s disease. It was developed for use by set dancing teachers. It is important to note that information provided in this booklet does not constitute training; instead, it is intended to act purely as an information source. It is up to each individual teacher to ensure they have adequate skills and knowledge before engaging in teaching set dancing to people with Parkinson's disease.

The information in this booklet was informed by set dancing teachers, people with Parkinson's disease, research evidence and professionals with expertise in this area. Great care has been taken to ensure the information provided is accurate and in accordance with best current evidence at the time of production. However, the developers and authors cannot guarantee the information provided is completely error free, especially since best practice guidelines are constantly changing. Therefore, the developers and authors accept no responsibility or liability for harm, damage or injury resulting from use of any information provided in this booklet. Users of this booklet are advised to seek assistance from other personnel or health care professionals if needed.

“Irish set dancing for people with Parkinson's disease: an information resource for set dancing teachers” publication may not be used for training purposes or as a single information resource. All rights reserved to developers and authors © 2016. Reproduction in part or full is prohibited without written authorisation of the copyright holder.
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Section 1

Introduction to Parkinson’s disease

“Health-related knowledge”1
1.1 What is Parkinson’s Disease?

Parkinson's disease is a neurological disorder affecting movement, cognition and balance. The cause of Parkinson's disease is loss of cells that produce a brain chemical called dopamine in part of the brain called the basal ganglia. There are many movement (motor) and non-movement (non-motor) symptoms associated with Parkinson's disease. Symptoms can be variable from person to person and progress over time.

1.2 Symptoms of Parkinson's Disease

Table 1 and Table 2 describe some of the motor and non-motor symptoms associated with Parkinson's disease. The potential effect each symptom may have on set dancing performance is also presented. Teaching methods to minimise the effect of symptoms on dancing performance and increase safety are discussed in Section 3 of this resource.

Motor symptoms

- The main motor symptoms of Parkinson's disease are tremor, bradykinesia and rigidity, affecting over 77% of those diagnosed. Postural instability and speech difficulties are also common and can negatively impact functioning.
- The severity of postural instability, mobility difficulties including slowness, shuffling walking pattern and freezing of gait increases with disease progression. As a result falls can become more prevalent occurring in 40-60% of those with Parkinson's disease.
<table>
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<tr>
<th>Symptom</th>
<th>Description of Symptom</th>
<th>Potential Effect on Set Dancing Performance</th>
</tr>
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<tr>
<td><strong>Bradykinesia:</strong></td>
<td>Slow movement which may affect any body part</td>
<td>Difficulty moving fast or taking longer steps</td>
</tr>
<tr>
<td><strong>Festinating of gait:</strong></td>
<td>Progressive reduction in the size of steps when walking</td>
<td>Steps may become shorter during longer movements. For example lead around</td>
</tr>
<tr>
<td><strong>Freezing:</strong></td>
<td>Difficulty walking, feet appear stuck to the floor</td>
<td>Can occur when turning Increased risk of falls</td>
</tr>
<tr>
<td><strong>Rigidity:</strong></td>
<td>Stiffness or resistance to movement</td>
<td>Slower to lift arms Slower to move at a faster pace</td>
</tr>
<tr>
<td><strong>Resting tremor:</strong></td>
<td>Rhythmic shake-like movement that can appear in the arms, legs, lips or neck when at rest</td>
<td>Usually does not affect dance performance Appears during rest</td>
</tr>
<tr>
<td><strong>Micrographia:</strong></td>
<td>Small writing</td>
<td>Reluctant to fill out forms</td>
</tr>
<tr>
<td><strong>Postural instability:</strong></td>
<td>Balance problems</td>
<td>At risk of falls</td>
</tr>
<tr>
<td><strong>Postural deformities:</strong></td>
<td>Forward bent neck, trunk, elbows or knees</td>
<td>Difficulty lifting arms high</td>
</tr>
<tr>
<td><strong>Dual task difficulties:</strong></td>
<td>Difficulty completing two tasks at once</td>
<td>Difficulty completing set movements and steps together</td>
</tr>
<tr>
<td><strong>Dyskinesia:</strong></td>
<td>Involuntary jerky movements that cannot be controlled by the person. These movements can occur as a side effect of medication used to treat Parkinson's disease</td>
<td>Increased risk of falls</td>
</tr>
<tr>
<td><strong>Speech difficulties:</strong></td>
<td>Slurred speech or low pitched tone when speaking</td>
<td>Unable to speak at high pitches and /or eluctant to engage in conversion</td>
</tr>
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</table>

For further information please see supporting references \(^2\text{-}^4\)

**Non-motor symptoms**

- Approximately 70% of those with Parkinson's disease experience non-motor symptoms. In the early stages of this condition,
depression, impaired memory and sleep disturbances are common.\textsuperscript{5} Anxiety, apathy and pain are also frequently reported.\textsuperscript{2, 5}

- Urinary incontinence and dementia may become more common with disease progression.\textsuperscript{5}

### Table 2 Non-Motor Related Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description of Symptom</th>
<th>Potential Effect on Set Dancing Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fatigue:</strong></td>
<td>Excessive tiredness during the day</td>
<td>Frequent rests may be needed during class.</td>
</tr>
<tr>
<td><strong>Pain:</strong></td>
<td>Pain can affect any part of the body</td>
<td>May negatively impact on dancing ability</td>
</tr>
<tr>
<td><strong>Urinary dysfunction:</strong></td>
<td>Urinary urgency or incontinence</td>
<td>Increased risk of soiling.</td>
</tr>
<tr>
<td><strong>Orthostatic hypotension:</strong></td>
<td>Drop in blood pressure with changing postures. For example when moving from sit to stand.</td>
<td>Can cause symptoms such as light headedness or fainting</td>
</tr>
<tr>
<td><strong>Psychiatric symptoms:</strong></td>
<td>For example impulsive control disorders, apathy or depression</td>
<td>Sudden behavioural changes, low motivation, lack of interest, reluctant to engage in conversion</td>
</tr>
<tr>
<td><strong>Cognitive disorders:</strong></td>
<td>For example dementia, bradyphrenia (slowness of thought) or impaired memory</td>
<td>Difficulty following instructions or remembering dance material, Slow to respond to instructions</td>
</tr>
<tr>
<td><strong>Sleep disturbances:</strong></td>
<td>For example nightmares or difficulty sleeping</td>
<td>Excessive tiredness</td>
</tr>
</tbody>
</table>

For further information please see supporting references\textsuperscript{2, 3, 5}
**Note: The influence of medication on motor symptoms**

The response of motor symptoms to Parkinson medication is commonly described by two transient phases called the "On" phase and "Off" phase. The "On" phase is a period of time where medication is working and movement ability is optimised. The "Off" phase is a period of time where movement ability decreases due to the wearing off of medication.  

"On"/"Off" medication phases need to be considered when dancing. To optimise dancing ability, classes should be scheduled during the “On” phase. The time of each individual’s “On” phase will differ but mid-morning and afternoon correspond to the most frequent On times.

### 1.3 Individuals Suitable to Participate in Set Dancing

The progression of symptoms associated with Parkinson’s disease is variable for every individual and may be defined by stages, described using the modified Hoeln and Yahr scale in Figure 1.  

**Figure 1 Modified Hoeln and Yahr Stages of Parkinson’s Disease**

![Diagram of Parkinson's Disease Stages]

Adapted from Goetz et al.  

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8
Set dancing is suitable for people at stages 1-2.5 on the modified Hoehn and Yahr Scale. Those at higher stages can have slower movement, greater balance instability and a higher risk of falls. A healthcare professional assesses the stage of Parkinson’s disease and an individual may need an assessment before starting dance classes. Observing dancers’ movement on entering class may indicate an individual’s suitability for set dancing participation.

Those who are visually impaired or unable to follow instructions due to reduced cognition may also be unsuitable to partake in set dancing.

1.4 Communicating with Individuals who may be Unsuitable for Set Dancing

If you have any concerns about an individual’s ability to join or continue set dancing:

- Speak to the individual privately (before and after the class)
- Seek their opinion on the class, for example expectations, prior experience and needs
- Communicate your concerns, for example balance instability when dancing, concerned about falls or injury. Discuss any measures that could be taken to ensure safe participation at their level of ability
- Advise the individual to seek advice from their General Practitioner or Physiotherapist to ensure they are suitable to take part
- After initial participation, ascertain if the class was too difficult or fast paced

1.5 Disease Progression: Cautions for Set Dancing

As the progression of Parkinson’s disease can negatively affect movement ability, activity levels, quality of life and increase the risk of falls, caution needs to be taken with the complexity of dance material to prevent falls.
Feedback from dancers will help guide the intensity of the class. In the event of a fall, the procedures in Table 3 should be followed.

**Table 3 Procedure to Follow if a Fall Occurs**

<table>
<thead>
<tr>
<th>Check the person is conscious and aware of their location and name</th>
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**Make sure there are no obvious signs of injuries including:**
- No broken bones. Pain when attempting to move or weight bear may indicate a broken bone
- Heavy bleeding
- Seizures

**If you do not suspect a serious injury:**
- Allow the person adequate time to recover
- Gradually, bring the person into a seated position. Give a drink of water and a sugary snack if the person feels weak
- Once the person is ready, allow them to stand
- If any symptoms remain, seek medical assistance

**If you suspect an injury or the person complains of pain on movement:**
- Do not move the individual unless in immediate danger. Keep them warm and as comfortable as possible
- Ask the person to keep still
- Call an ambulance for assistance
- Apply pressure to wounds that are bleeding
- Do not restrain a person during a seizure

**If the person is unconscious, breathing and has a pulse**
- Call the ambulance and roll in the recovery position if trained

**Also call an ambulance if there are signs of:**
- Difficulty breathing
- Drowsiness
- Concussion including dizziness, disorientation, vomiting or visual disturbance.
- Excessive sleepiness
- Abnormal walking pattern: e.g. example balance problems
- Unusual symptoms or behaviour

**If a person is unconscious, has no pulse or is not breathing**
1.6 Sudden Deterioration

- People with Parkinson’s disease may also experience a sudden deterioration i.e. from one week to the next in movement or balance.
- Those with a sudden deterioration in symptoms may have a high risk of falls.
- Therefore, caution needs to be taken in a dance class and the complexity of the dance material or the tempo of music may have to be modified to ensure safety.
- Those with a sudden deterioration may fatigue quicker and require more frequent rests.
- Individuals with a sudden deterioration in health should consult their doctor.

Table 4 outlines some factors that may cause a sudden deterioration in symptoms.

<table>
<thead>
<tr>
<th>Table 4 Potential Causes of Sudden Deterioration</th>
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</thead>
<tbody>
<tr>
<td>Constipation</td>
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<tr>
<td>Illness/infection</td>
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<tr>
<td>Stress</td>
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<tr>
<td>Dehydration</td>
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<tr>
<td>Changes in medication regime</td>
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<tr>
<td>Use of contra-indicated drugs</td>
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<tr>
<td>Depression</td>
</tr>
<tr>
<td>Pain</td>
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<tr>
<td>Anxiety</td>
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<tr>
<td>Lack of sleep/poor sleep</td>
</tr>
</tbody>
</table>
Section 2

The Benefits of Set Dancing for People with Parkinson’s Disease

“To be active and to be connected to people”\textsuperscript{14}

“It has given me hope”\textsuperscript{15}

“Dancing makes you feel alive”\textsuperscript{1}
2.1 Potential Benefits of Irish Set Dancing for Individuals with Parkinson’s Disease

Exercise is important for maintaining and improving muscle strength, balance, walking ability and everyday function and reducing falls in people with Parkinson’s disease. As a form of exercise Irish set dancing has many potential benefits for people with Parkinson's disease:

- Set dancing steps such as the reel step are similar to the pattern of walking and may improve mobility in people with Parkinson’s disease.
- The cultural and social aspect of set dancing facilitates an energetic atmosphere and may improve quality of life, reduce social isolation, improve mood and motivate regular participation in set dancing classes.
- The social aspect of set dancing also allows participants to form friendships. These friendships can offer peer support and help improve social confidence.
- Set dancing can provide a distraction from anxieties or worries.
- Partnering in set dancing provides a sense of safety and may reduce fear of falling.
- The multi-directional movements in set dancing may improve balance.
- Irish dance music provides a predictable rhythmic beat. This may act as an external cue to synchronise the timing of movements helping to make them faster and larger.
- Music may complement the beneficial effects of dancing by stimulating brain chemicals dopamine and serotonin. This may help improve mood, alleviate anxiety and evoke a sense of satisfaction and enjoyment.
- Set dancing can afford benefits for spouses and caregivers by providing an opportunity to socially interact, improve physical health and gain support and advice from other people affected by Parkinson’s disease.
“It’s not just yourself and not even a couple. There is solidarity in a set...that you’ll...help each other out, a feeling of accomplishment”¹⁴
Section 3
Key Considerations for Teaching Set Dancing to People with Parkinson’s Disease

“It does not matter who you are, everybody talks to each other”
“The primary motive is just the craic that goes on”\textsuperscript{14}

“It made us feel stronger and better able to cope”\textsuperscript{16}
3.1 Class Structure: Part 1 (Warm-Up)

It is recommended that a warm-up is performed at the start of class. The purpose of a warm-up is to prepare the body for dancing. Warm-up exercises should include a range of different exercise types. For set dancing a warm up should include:9, 10, 27-29

- Joint movement exercises
- Cardiovascular exercises
- Muscle endurance exercises
- Balance exercises

For people with Parkinson’s disease a warm-up is particularly important because of:

- Increased muscle stiffness (rigidity)2
- Lower activity levels30

Table 5 displays sample warm-up exercises.9, 27, 31, 32 This list provides examples of exercises to illustrate the principles of a warm-up. Many other exercise possibilities are available.
### Table 5 Sample Warm-Up Exercises

#### Exercise Type 1: Joint Movement Exercises

**Aim:** To promote joint movement and posture

- Gently lift both arms out to the side and overhead. Go as far as is comfortable and painfree.

**Hint:** Sit up tall on a chair for these exercises. Good posture facilitates shoulder movement.

**Warning:** A chair can be used for support during these exercises.

- Swing one leg gently back and forward with big movements.
### Exercise Type 2: Cardiovascular, Muscular and Balance Exercises

**Aim:**
1. To prepare the cardiovascular system and muscles for set dancing.
2. To promote muscular and balance ability required for set dancing

- Side step to one side 5 times. Take large steps. Repeat in the other direction

- Walk up and down the hall, taking long steps. Swing arms as you walk

**Hint:** To increase the difficulty of these exercises, increase the speed of music in line with dancers’ ability.
General guidelines for a warm-up

- Cues can help people with Parkinson's disease maintain normal movement patterns.\textsuperscript{33, 34} Table 6 presents a list of some cues that may be used during a dance class

<table>
<thead>
<tr>
<th>Aim of cues</th>
<th>Examples of cueing technique:</th>
</tr>
</thead>
<tbody>
<tr>
<td>To facilitate normal movement through the provision of an external cue and prevent:</td>
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<tr>
<td>1. Festinating gait</td>
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<tr>
<td>2. Freezing episodes</td>
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<tr>
<td>3. Balance instability</td>
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</tbody>
</table>
| **Type of cues:** | \begin{itemize}
| 1. Visual cues | - Demonstrate steps and movements
| - Place a ruler on the ground and instruct an individual experiencing an episode of freezing to step over it when ready |
| 2. Verbal cues | - Verbally sing rhythmic beats
| - Give instruction to take “big or long steps”
| - Give instruction to place one foot in front of the other when walking and dancing movements |
| 3. Auditory cues | - Music
| - Metronome |
| Note: This is very important during advance and retire and turning movements to reduce the risk of falling backwards |

For additional information, please see supporting references\textsuperscript{1, 33}

- Perform simpler exercises first and progress in line with dancers’ abilities\textsuperscript{9}
- Pace exercises in line with the dancers’ severity of Parkinson’s disease and current exercise involvement\textsuperscript{35}

19
- Get feedback from dancers regarding the complexity of exercises. This will inform the selection of exercises for the class\(^\text{35}\)
- Instruct dancers to move at their own pace\(^\text{36}\)
- Repeat exercises on both right and left sides of the body
- Repeat each exercise 10 times
- Demonstrate new exercises. To optimise learning, demonstrate exercises in two positions, facing dancers and turned sideways
- Position chairs beside each dancer to use for support or to practice exercises sitting down\(^\text{37,38}\)

### 3.2 Class Structure: Part 2 (Set Dancing)

This section provides information that will help implementation of a set dancing class for people with Parkinson’s disease

**Safety Tips before you start a class for people with Parkinson’s disease**

- Space should be sufficient. Remove extra furniture as clutter and obstacles can cause freezing and trips\(^\text{4,39}\)
- Don’t dance on slippery floors such as tiles
- Lighting must be sufficient to see properly\(^\text{39}\)
- Partner those with Parkinson's disease with those without Parkinson’s disease
- Give breaks to minimise fatigue and get feedback regarding the number and length of breaks\(^\text{40,41}\)
- Ensure all participants keep hydrated
- Toilet breaks are important due to incontinence issues\(^\text{2}\) (jumping can increase stress on bladder muscles)
- Do not try to move or push an individual experiencing festinating (progressive reduction in step size) or freezing (feet appear stuck to the ground) of gait. Stand close to the individual to protect against falls. Advise the individual to take a long step when ready. Other visual cues described in Table 6 can also be used
Note: If anyone becomes dizzy or feels faint:

- Lie the person down with their legs raised and supported
- Sit the individual up once recovered
- Give a drink of water
- Give a sugary snack if symptoms have not passed
- Gradually allow the person to stand as able
- If symptoms do not pass, seek medical advice immediately

If anyone complains of any other adverse effects advise them to seek medical advice

Adapted from the American Heart Association and American Red Cross First Aid Guidelines and the National Health Service Fainting Treatment Guideline\(^{12,42}\)

Teaching tips

- Break down steps and set movements into small components. This facilitates learning and prevents abnormal movement patterns\(^{9}\)
- Verbal and visual cues help overcome freezing, increase speed of movement and facilitate learning.\(^{3,25}\) Please see Table 6 for some cueing techniques that may be used
- Timing the music correctly is important to prevent festinating gait and freezing\(^{25,43}\)
- Smaller square size in set dancing may increase freezing symptoms due to space constriction.\(^{4}\) A larger square size is preferable and dancers may move half way across the set when dancing or as far as are able

Examples of beneficial and simpler dance movements for people with Parkinson's disease include:

- Lead around
- Pass through
- Circle
- House at home
- Ladies chain
- Advance and retire movements

Examples of harder dance movements for people with Parkinson’s disease include:

- Swing

“Involvement in dance facilitates a growth of confidence”\(^{1}\)
Round the house

Other movements that are fast paced or involve repeatedly turning

Simplify difficult or fast paced movements to increase safety. For example:

- Only do one turn in a dance at home
- Complete a movement in 8 bars of music instead of four bars

Begin with simpler sets. Harder parts/movements may be temporally omitted if needed and included at a later date in line with dancers' ability. Appendix A gives an example of how you might introduce people with Parkinson's disease to simpler set movements.

More complex movements may be taught if dancers are comfortable with easier material and have the balance stability to perform movements safely.

If a dancer shows signs of fatigue or loss of balance, starts to take shorter steps or freezes, the tempo may be too fast or the movement too hard or a rest may be needed.

Consider the age of dancers when deciding on dance material. Older individuals may have more balance difficulties or move slower.

If dancers wish to formally assess the beneficial effects of set dancing consider using Activities Balance Confidence Questionnaire (Appendix B). This questionnaire provides a self-assessment of balance confidence during daily activities.

Tempo of music:

- Slow tempo initially in line with dancers' ability and knowledge of steps/sets
- Prevent injury and falls by keeping music tempo in line with dancers' abilities
- Increase tempo gradually as tolerated
- People with Parkinson’s disease may need longer to learn and retain steps/sets\(^{16}\)
- Get feedback regarding the complexity of dance material and tempo of music\(^{35}\)

**Making the class enjoyable**

Enjoyment is one of the most beneficial effects of set dancing and it is important to create a relaxing and sociable environment at classes.\(^{14, 24, 35}\) Remember to:

- Allow time for conversation\(^{35}\)
- Motivate and give encouragement
- Repeated practice can facilitate learning new movements\(^{35, 47}\)
- Work individually with people who are having difficulty\(^{35}\)
- Experienced dancers at the class can increase the social aspect. People with Parkinson’s disease may learn from experienced dancers by observing their dancing\(^{35}\)
- For individuals with speech difficulties, listen attentively during conversations and ensure they are involved in the social aspect of class

"Dance is more than just exercise”\(^{9}\)

"It’s like an achievement”\(^{16}\)

**3.3 Class Structure: Part 3 (Cool Down)**

Muscle stretches are at the end of class to help prevent muscle stiffness and soreness.\(^{48}\) Table 7 displays examples of seated stretches\(^{31}\) but there are many other possibilities available.
<table>
<thead>
<tr>
<th><strong>Table 7 Stretches</strong></th>
</tr>
</thead>
</table>

**Note:** Stretches should be comfortable and pain free. Do not push in to pain when stretching.

- Sit, with one leg straight out as shown. Keep knee straight. Pull toes gently toward head. A comfortable stretch in the lower leg should be felt. Hold for 7 seconds. Repeat on both legs 3 times.

- Sit, with one leg straight out as shown. Keep knee straight. Pull toes gently toward head. Reach hand down toward toes as far as able. Do not over reach and cause pain. A comfortable stretch in the back of the leg should be felt. Hold for 7 seconds. Repeat on both legs 3 times.

**Hint:** Hold onto the chair with the free hand for support of needed

- Sit half way forward on a chair. Hold the back of the chair with both hands. Keep back straight. A gentle stretch should be felt in the front of the chest. Hold for 7 seconds and repeat 3 times.
3.4 How Long to Dance for?

- Research has found that classes of 1-1.5 hours long, twice per week can be beneficial.\textsuperscript{45} Longer classes may exacerbate fatigue.
- For safety and to maximise learning, the intensity of the dance class should start low.
- Increase intensity as dancers become familiar with the material.\textsuperscript{9,27}
- Get feedback regarding the appropriate tempo of music and complexity of material taught.
- Classes should be at least 10-13 weeks but longer durations may be more beneficial.\textsuperscript{45}
“The classes were fun and exciting and we looked forward to the classes every week”\textsuperscript{1}
Bibliography


15. Flynn N. To investigate patient’s perceptions of Irish set dancing as a treatment intervention in the Parkinson’s disease population: University of Limerick; 2015.


Glossary of Set Dancing Terms

**Gent:** The male partner of the dancing couple. The gent is positioned to the left of his dancing partner.⁴⁹

**Lady:** The female partner of the dancing couple. The lady stands to the right of her dancing partner.⁴⁹

**Tops:** Two dancing couples that stand opposite each other in a set. One top couple will stand facing the musicians. The other top couple will have their back to the music.⁴⁹

**Side:** Two opposite facing couples that are positioned to the right and left of the top couples.⁴⁹

**Square size in set dancing:** Distance between four couples, positioned to form a square with all dancers facing inwards.

**Lead around:** All couples dance anticlockwise around the set. Gents are on the inside.⁵⁰

**Pass through:** Two facing couples dance across the set, turn, and dance back to place. Gents pass through on the outside of the ladies with their right shoulder.⁵⁰

**Circle:** All eight dancers hold hands and advance and retire twice.⁵⁰

**House at home (dance at home):** In the waltz hold, partners dance in an clockwise direction in their own place, turning twice.⁵⁰

**Ladies chain:** Two ladies take right hands in the centre of the set. Ladies drop hands. Give left hand to opposite gent and dance around anticlockwise to the
opposite lady’s place. Drop hands and cross home passing right shoulders with the opposite lady.\textsuperscript{50}

\textbf{Advance and retire movements} Partners take crossed hands (right hands on top). Dance towards the centre of the set (4 bars) and back to place without turning (4 bars).\textsuperscript{50}

\textbf{Swing:} In the waltz hold, partners complete four turns in their own place (8 bars). To complete this movement, right feet are positioned in front with the gent’s foot on the inside. The left heel is raised off the ground. Place weight through the right foot on the 1\textsuperscript{st} and 3\textsuperscript{rd} beat of each bar. Place weight through the left foot on the 2\textsuperscript{nd} beat of every bar.\textsuperscript{51}

\textbf{Round the house:} In the waltz hold, partners dance in an anticlockwise direction around the set, turning four times.\textsuperscript{50}
Appendices

Appendix A
The following is an example of a simplified set for those with Parkinson’s disease which was based on the Connemara Set.

Starting Positions in a Set

First Figure (160 bars)
1. All couples take crossed hands. Dance anticlockwise around the set and back to place. All couples turn in place and lead back around the set in a clockwise direction. Finish in place. (16 bars)
2. All swing or dance at home with one turn. (8 bars)

3. Top couples: Take crossed hands and advance and retire twice. (8 bars)

4. Top couples: Lead around with crossed hands. Finish in place. (8 bars)
5. Top couples: Swing or dance at home with one turn. (8 bars)

6. Side couples dance step 3 to 5. (24 bars)

7. Top couples: Ladies chain with ladies crossing right shoulders in the middle of set, around the opposite gent and back to place. Swing or dance at home with one turn. (16 bars)

8. Side couples: Dance step 7. (16 bars)

9. Top couples: Repeat step 3 to 5. (24 bars)

10. Side couples: Repeat step 3 to 5. (24 bars)
11. All swing or dance at home with one turn. (8 bars)

Second Figure (192 bars)

1. All couples take crossed hands. Dance anticlockwise around the set and back to place. All couples turn in place and lead back around the set in a clockwise direction. Finish in place. (16 bars)
2. All swing or dance at home with one turn. (8 bars)

3. Top couples dance back-to-back: 1st gent and opposite lady dance a circle around the centre of the set, right shoulder to right. (8 bars)
4. Swing or dance around in the waltz hold turning once in the centre of the set. Reverse back to place for the last 2 bars. (8 bars)

5. Top couples: Advance and retire twice, holding crossed hands with your partner. (8 bars)

6. Top couples: Lead around holding crossed hands with your partner. (8 bars)
7. Top couples: Swing or dance at home with one turn. (8 bars)

8. Side couples: Repeat step 3 and 4 with 1st side gent and opposite lady. (16 bars)

9. Side couples: Repeat step 5 to 7. (24 bars)

10. Top couples: Repeat step 3 and 4 with 2nd top gent and opposite lady. (16 bars)

11. Top couples: Repeat step 5 to 7. (24 bars)

12. Side couples: Repeat step 3 and 4 with 2nd side gent and opposite lady. (16 bars)

13. Side couples: Repeat step 5 to 6. (16 bars)
14. All swing or dance at home with one turn to finish. (8 bars)

Third Figure (184 bars)

1. All circle, advancing and retiring twice. (8 bars)

2. All swing or dance at home with one turn. (8 bars)
3. 1st top couple: Gent’s place right hand on ladies back, lady’s place left hand on gent’s right shoulder. Advance towards the centre of the set, retire and advance again to finish in the middle of the set. (8 bars)

4. In the middle of the set, swing or dance around in the waltz hold turning once. (8 bars)
5. Both top couples dance in a circle around the centre of the set once, anticlockwise. Dance back to place. (8 bars)

6. Top ladies chain. (8 bars)

7. Tops swing or dance at home with one turn. (8 bars)
8. 1st side couple: Dance step 3 and 4. (16 bars)

9. Side couples: Repeat step 5 to 7. (24 bars)

10. 2nd top couple: Repeat step 3 and 4. (16 bars)

11. Top couples: Repeat step 5 to 7. (24 bars)

12. 2nd side couple: Dance step 3 and 4. (16 bars)

13. Side couples: Repeat step 5 and 6. (16 bars)

14. All swing or dance at home with one turn to finish. (8 bars)
Appendix B

Activities Balance Confidence Scale (ABC)

**Aim:** This questionnaire asks you to rate your balance confidence when performing a range of daily activities.5

**Instructions:** Please indicate, by placing a tick in the appropriate box, how confident you feel you can complete each of the following activities without losing your balance or feeling unsteady. Please use the scale 0%-100% to indicate your level of confidence when performing each activity.

- 0% = No balance confidence when completing this task or you feel very unsteady.
- 100% = Completely confident, no balance issues when completing this activity.

**Scoring the questionnaire when you are finished**

Add up the total of your scores and divide by 16

- Re-do the questionnaire in 2-3 months and compare your results for each question or your total score.
# Questionnaire Sheet

**Name:**    
**Date:**    
**Time:**    

How confident are you that you will not lose your balance or become unsteady when you:

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
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<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
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<tbody>
<tr>
<td>1. Walk around the house?</td>
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<td>2. Walk up or down stairs?</td>
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<td>3. Bend over and pick up a slipper from the front of a closet floor?</td>
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<td>4. Reach for a small can off a shelf at eye level?</td>
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<td>5. Stand on your tip toes and reach for something above your head?</td>
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<td>6. Stand on a chair and reach for something?</td>
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<td>7. Sweep the floor?</td>
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<td>8. Walk outside the house to a car parked in the driveway?</td>
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<td>9. Get into and out of a car?</td>
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<td>10. Walk across a parking lot to the mall?</td>
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<td>11. Walk up or down a ramp?</td>
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<td>12. Walk in a crowded mall where people rapidly walk past you?</td>
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<td>13. Are bumped into by people as you walk through the mall?</td>
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<td>14. Step onto or off of an escalator while you are holding a railing?</td>
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<td>15. Step onto or off of an escalator while holding onto parcels such that you cannot hold onto the railing?</td>
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<td>16. Walk outside on icy sideways?</td>
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Appendix B: Patient Information Leaflet for Feasibility Study

A study to determine the feasibility of Irish set dancing for people with Parkinson’s disease in Ireland

**Patient Information Leaflet**

**Introduction**

The aim of this study is to investigate if the feasible of Irish set dancing for people with Parkinson’s disease in Ireland.

**Procedures**

Participants who agree to take part in the study will take part in set dancing classes and continue with their usual care.

No additional exercise or dancing classes should be taken up during the research study. In addition the main researcher must be informed if your usual medication regime changes during the study.

You and your main care giver will also be asked to attend the University of Limerick for a short assessment before and immediately after the set dancing classes. These assessments will take approximately one hour to complete.

The set dancing classes will run for eight weeks and will take place in the University of Limerick. The classes will last an hour and a half and will be thought by a set dancing teacher who is also a chartered physiotherapist. You can bring a dance partner to the class. This can be a family member, spouse or carer. A home dance exercise programme will also be given to you to take part in.
Benefits
Set dancing may help to improve your walking and enable you to move easier so that daily tasks can be performed easier.

Risks.
There are no serious risks associated with this study. There is a minor risk of slipping while dancing, however, this risk is reduced as you will be dancing with a dance partner at all times.

Those unaccustomed to exercise may experience some muscle soreness. However, a gentle warm up and cool-down will be performed at every class to allow the body to gradually adjust to exercise. There will also be frequent rest periods during the dance class to ensure that muscles do not get fatigued. You are also free to sit and rest at any time during the class if you need to.

Exclusion from Participation
You will not be able to participate in this study if you have:

- a serious cardiovascular and/or pulmonary condition
- a neurological deficit other than Parkinson’s
- Evidence of a musculoskeletal problem contraindicating participation in exercise participation
- a cognitive or hearing problem which affect your ability to follow instructions or hear the music
- participated in a regular dance class in the past six months

You will be able to participate if you:

- have a diagnosis of idiopathic Parkinson’s, stage 1-2.5 on the modified Hoehn and Yahr scale for staging of Parkinson’s disease
- are showing a clear benefit from your anti-Parkinson medication
- are able to walk three meters without an assistive device
• are not pregnant
• are over 18 year of age
• have a TV and DVD player in their own home to allow you to participate in
  the home exercise programme.

Alternate Treatment
This study is investigating the effect of set dancing in people with Parkinson’s
disease. This study does not offer an alternate treatment if you do not wish to attend
set dancing classes. However, you are not obliged to participate in the study if you
do not wish to.

Confidentiality
All personal information is confidential. Your name will not be attached to any data.
All participants’ names will be written in a log book and matched with an
identification code. The log book will be stored in a secure location. The
identification code will be used on all assessment sheets. The anonymised
information gathered will be analysed in appropriate statistical tests and presented as
the results of the study. All data will be stored in a locked cabinet in the office of the
main researcher.

Permission
You will be asked to give permission to allow your clinical nurse specialist to
disclose the following information to the main researcher:

• The duration of you condition
• Stage of your disease to the main researcher.
• The type and dosage of your anti-Parkinson’ medication
• Your general practitioner’s name and address so that they can be informed
  that you are participating in the study.

Compensation
There will be no financial reward for participating in this study.
Voluntary Participation and Stopping the Study
You are not obliged to participate in this study. You may leave the study at any time if you wish without giving any reason. If for any reason you and other participants feel that the intervention is having adverse effects on your health or quality of life the study will be stopped.

Further Information
If you have any further queries, please contact one of the research team:
Joanne Shanahan: Joanne.Shanahan@ul.ie
Dr. Amanda Clifford: Amanda.Clifford@ul.ie
Dr. Orfhlaith Ni Bhriain: Orfhlaith.NiBhriain@ul.ie

Complaint Procedure
If you have any concerns or complaints about this study and wish to contact someone independent, you may contact The Chairperson of the Mid-Western Ethics Committee.

The Chairperson, Scientific Research Ethics Committee, Limerick Regional Hospital, Dooradoyle, Limerick.
Appendix C: Informed Consent Form for Feasibility Study

A study to determine the feasibility of Irish set dancing for people with Parkinson’s disease in Ireland

Informed Consent Form

Please tick the box if you agree with the statement:

- I have read and fully understand the subject information sheet.
- I understand that my participation is voluntary and that I can withdraw from the project at any stage without giving any reason.
- I give permission to the research team to access the relevant medical information required for the study as described in the patient information sheet.
- I give permission to the research team to inform my G.P. that I am participating in the study.
- I understand that I must inform the research team immediately of any adverse effects experienced due to my participation in the study.
- I am aware that my results will be kept confidential.
- I agree to participate in this study.

Signature: ___________________________ Date: ________________
Printed: ___________________________ Date: ________________
Witness Signature: __________________ Date: ________________
Witness Printed: ____________________ Date: ________________
Investigator’s Signature: ______________ Date: ______________
Investigator’s Printed: _______________ Date: _______________
Appendix D: Letter for General Practitioner Approval for Feasibility Study

A study to determine the feasibility of Irish set dancing for people with Parkinson’s disease in Ireland

Dear Dr._______________

(Patient’s name) has volunteered to participate in a research study entitled “A study to determine the feasibility of Irish set dancing for people with Parkinson’s disease in Ireland”. This study is being carried out by researchers at the University of Limerick in collaboration with Prof Meg Morris at LaTrobe University in Melbourne, Australia and Dr Danielle at St John of God Hospital Parkinson's Centre in Venice, Italy.

The aim of the study is to investigate the feasibility of set dancing classes for people with Parkinson’s disease in Ireland.

All participants will undergo assessments of functional exercise tolerance, balance, motor performance and quality of life and will participate in set dancing classes for eight weeks.

To ensure eligibility to participate in this study all volunteers will be reviewed by the Parkinson’s clinical nurse specialist and by the main researcher. In addition as (patient’s name) general practitioner could you please indicate below if she is eligible to participate in this study and return your response to me as soon as
possible. I have enclosed a stamped addressed envelope for your convenience. I have listed the inclusion and exclusion criteria below.

Participants will be eligible to participate if they meet the following inclusion criteria:

- Have a diagnosis of idiopathic Parkinson’s disease, stage 1-2.5 on the modified Hoehn and Yahr scale for staging of Parkinson’s disease
- Showing a clear benefit from anti-Parkinson medication
- Able to walk three meters without an assistive device
- Not pregnant
- Over 18 year of age
- Have a TV and DVD player in their own home to allow them to participate in the home exercise programme

Participants will be excluded from the study if they have:

- a serious cardiovascular and/or pulmonary condition
- a neurological deficit other than Parkinson’s disease
- evidence of a musculoskeletal problem contraindicating participation in exercise participation
- a cognitive or hearing problem which will effect their ability to follow instructions or hear the music
- participated regularly in a dance class in the past six months

\(\text{Patient’s name}\)____ is suitable to participate in this study.  
\(\text{Patient’s name}\)____ is not suitable to participate in this study.

I have enclosed a copy of the patient information leaflet which outlines the study in more detail. Please do not hesitate to contact me or any member of the research team if you have any queries regarding this study.
Yours sincerely

__________________________
Joanne Shanahan, MISCP
PhD. Candidate,
Department of Clinical Therapies,
Faculty of Education and Health Sciences,
University of Limerick,
Limerick
Email: Joanne.Shanahan@ul.ie

Dr. Amanda Clifford, MISCP
Department of Clinical Therapies,
Faculty of Education and Health Sciences,
University of Limerick,
Limerick,
061234118
Email: Amanda.Clifford@ul.ie

Dr. Orfhlaith Ní Bhriain,
Irish World Academy of Music and Dance,
University of Limerick,
061 20 2470
E-mail: Orfhlaith.NiBhriain@ul.ie
Appendix E: Development of the Set Dance Based Home Programme

PowerPoint Presentation

A Dance-Based Home Exercise for People with Parkinson’s Disease
A dance based home exercise programme for people with Parkinson’s disease

Joanne Shanahan, Physiotherapist, PhD researcher, set dancing teacher.

26th March 2015

Acknowledgements

• PhD supervisors:
  - Dr. Amanda Clifford, Department of Clinical Therapies, University of Limerick
  - Dr Orfhlaith Ní Bhriain, Irish World Academy of Music and Dance, University of Limerick,
  - Prof Meg Morris, La Trobe University, Melbourne, Australia.

ILM Supervisor:

- Dr Nancy Salmon, Department of Clinical Therapies, University of Limerick
Aim of ILM/Presentation

Describe and present the process of development of the dance based DVD home exercise programme.

Outline of Presentation

- Introduction to Parkinson’s disease
- Dance for people with Parkinson’s disease
- Overview of my PhD research project - *Why a home exercise programme?*
- Development of home exercise programme
- Feasibility testing
- Modification and re-evaluation of home exercise programme
Parkinson’s Disease

- Parkinson’s disease is a progressive neurodegenerative condition characterised by a deficiency of the neurotransmitter dopamine in the Substantia Nigra of the Basal Ganglia (Keus et al 2004).
- Parkinson’s disease affects approximately six million people worldwide (Morris et al 2010).
- Clinical features: bradykinesia (slow movement), rigidity and resting tremor (Keus et al 2004).
- As the disease progresses postural instability and mobility difficulties can have a compromising effect on physical functioning, quality of life, family and social engagement (Clair et al., 2012).

Why Dance for People with Parkinson’s Disease?

**Similar components to rehabilitation programmes:**
- Cueing
- Challenges balance and physical capacity
- Attentional focus

**Social activity:**
- Relaxation
- Enjoyment
- Implications for quality of life

(Earhart 2009; Foster et al 2013)

**Research to date:**
- Much of the research has focused on Tango and different types of modern dance
- Improvements reported in motor impairment, mobility, balance, quality of life

**Set dancing:**
- Only one study has investigated the feasibility of set dancing in a sample of Venetians with Parkinson’s disease
- Improvements reported in balance and mobility (Volpe et al 2013)
- However ...............
Research Gap and Questions

1. Further research is needed to confirm the findings of Volpe et al (2013)

1. No study has determined if:

   • Set dancing is feasible and beneficial for an Irish population with Parkinson’s disease
   • This is important as set dancing has a rich cultural heritage in Ireland and is associated with social and community interactions

   *(Lynch 1989; Lynch 2011)*

Systematic Review

Systematic Review

Aim: Provide information regarding an appropriate frequency, intensity, duration and type of dance (FITF principle).

Results:
- **Frequency**
  - Two, one hour dance classes per week
- **Duration**
  - Ten to thirteen weeks may have beneficial effects on motor impairment, endurance and balance
  - Longer durations may be more beneficial
- **Intensity**
  - Not reported
- **Type**
  - A variety of dance types appear to be helpful eg. Tango and Waltz/Fox trot but more higher quality studies are needed to determine the effectiveness of other dance genres

Problem, Thinking and Solutions

**Solution**
- A dance based home exercise programme

**Why?**
- Increase participation in dance: Facilitate learning
- Feasible

**Previous research**
- Improve balance, quality of life
- Reduce rate of falls
- Feasible (79% compliance)

(Ashburn et al 2006; Novos et al 2009; Roche et al 2009)
Factors to Consider when Developing the Home Dance Programme

1. Evidence based
   » Integrate evidence from dance and exercise for people with Parkinson’s disease
   » Complement the dance class (Structure, chosen material)

2. Motivating
   » Encourage participation

3. Safety / Injury Prevention
   » Dance/exercise injury prevention strategies
   » Exercise tolerance (fatigue)

4. Appropriate / Specific for people with Parkinson’s disease
   » Freezing/Festinating gait
   » Postural instability (caution: backward movement)
   » Muscle rigidity

Feasibility testing

Methods

**Aim:** To investigate if community-based Irish set dancing is feasible for Irish adults with idiopathic Parkinson’s disease.

**Design:** A single group, before-after feasibility study.

**Outcome measures:**
- Berg balance scale,
- Six-minute walk test,
- UPDRS-3
- PDQ-39

**Feasibility:**
- Monitoring adverse effects
- Participants’ verbal feedback and feedback from an exit questionnaire
- Attendance rates at classes and compliance with home exercise diary (home exercise diary)

---

**Methods**

**Sample:** n=10

**Intervention:**
- Delivered by set dancing teacher who is also a Chartered Physiotherapist
- 1.5hrs once per week for eight weeks
- Continued with usual care and ADL’s
- Home dance programme 2x20 mins per week (DVD)
Demographic Profile (n=9)

- Data from one participant excluded due to medication changes

<table>
<thead>
<tr>
<th>Age</th>
<th>66.66 ± 5.87</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoehn and Yahr</td>
<td>1.5 ± 0.5 (1, 2.5)</td>
</tr>
<tr>
<td>Gender (male:female)</td>
<td>7:2</td>
</tr>
<tr>
<td>Duration of disease (years)</td>
<td>7.3 ± 5.96</td>
</tr>
<tr>
<td>Previous set dance experience</td>
<td>43%</td>
</tr>
</tbody>
</table>

Values for age and duration of disease are mean ± standard deviation. Values are Hoehn and Yahr and duration of disease as median ± interquartile range (minimum, maximum).

Results for Home Programme

- Participation in home programme: 67.34% (2*20 min per week)
- No adverse effects reported

Verbal feedback
- Participants felt the home programme was “too simple”
- More challenging if they could practice in standing.
- Liked listening to the music
- Felt mental rehearsal was unstimulating and “boring” and would have preferred to actively dance.

Participation in the home programme was affected by these issues and family events.
## Results-Outcome Measures

<table>
<thead>
<tr>
<th></th>
<th>Baseline (n=9)</th>
<th>Post Intervention (n=8)</th>
<th><em>P</em> value</th>
</tr>
</thead>
<tbody>
<tr>
<td>UPRRS-3</td>
<td>11±7.5 (6.25)</td>
<td>9±3 (4.18)</td>
<td>0.03</td>
</tr>
<tr>
<td>PDQ-39</td>
<td>23.30±17.46 (4.59, 36.82)</td>
<td>19.27±15.93 (3.08, 31.41)</td>
<td>0.01*</td>
</tr>
<tr>
<td>6MWT (meters)</td>
<td>388.41±100.24 (288.19, 513.73)</td>
<td>388.43±91.98 (288.19, 476.14)</td>
<td>0.24</td>
</tr>
<tr>
<td>Berg</td>
<td>55±2.50 (52, 56)</td>
<td>56±2.50 (53, 56)</td>
<td>0.1</td>
</tr>
</tbody>
</table>

*Wilcoxon Signed Ranks Test. Results are median±interquartile range (minimum, maximum)*

UPDRS-3=Unified Parkinson’s Disease Rating Scale – Motor subscale; 6MWT= 6-Minute Walk Test; Berg= Berg Balance Test

## Results-Feasibility

- Attendance: 86.11% (8 sessions)
- No adverse effects reported

*Exit Questionnaire*

<table>
<thead>
<tr>
<th>Questionnaire item</th>
<th>Median (min, max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I enjoyed participating</td>
<td>1 (1, 1)</td>
</tr>
<tr>
<td>My balance improved</td>
<td>2 (2, 4)</td>
</tr>
<tr>
<td>My walking has improved</td>
<td>2 (1, 3)</td>
</tr>
<tr>
<td>My usual improved</td>
<td>2 (1, 3)</td>
</tr>
<tr>
<td>My coordination improved</td>
<td>2 (1, 3)</td>
</tr>
<tr>
<td>My strength improved</td>
<td>2 (2, 4)</td>
</tr>
<tr>
<td>My endurance improved</td>
<td>2 (1, 3)</td>
</tr>
<tr>
<td>I would continue classes if offered</td>
<td>1 (1, 3)</td>
</tr>
<tr>
<td>I use ideas/skills learned in classes in ADUS</td>
<td>3 (1, 3)</td>
</tr>
</tbody>
</table>

(1=strongly agree; 2=somewhat agree; 3=neither agree nor disagree; 4=somewhat disagree; 5=strongly disagree)
Re-testing


Changes to Methods

1. Changes to home programme
   - Exercises chair-based
     (Supported standing, standing,
      use of chair as visual cue)
   - Dosage: 3×20mins per week
   - Difference in material taught:
     Exercises more complex and
     higher intensity

2. Multi-centered randomised controlled trial with an intervention and control group

Total Sample size = 100
Conclusion

- People willing to take part in a home dance programme
- Feasible way to increase dosage of dance practice
- Modifications are needed to increase participation

Thank You

https://www.facebook.com/groups/5510
38925028901/
References


References


References

Appendix F: Home Exercise Diary for Feasibility Study

A study to determine the feasibility of Irish set dancing for people with Parkinson’s disease in Ireland

Name:

**Home Dance Diary**

Please fill in below how much time you spend completing your home exercise programme. Try to do two 20 minute sessions each week.

<table>
<thead>
<tr>
<th></th>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1</td>
<td></td>
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<tr>
<td>Week 2</td>
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<td>Week 3</td>
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<tr>
<td>Week 4</td>
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<tr>
<td>Week 5</td>
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<tr>
<td>Week 6</td>
<td></td>
<td></td>
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<tr>
<td>Week 7</td>
<td></td>
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</tr>
<tr>
<td>Week 8</td>
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</tbody>
</table>
Appendix G: Protocol for a Randomised Controlled Pilot Trial
Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease- In Line with the CONSORT Statement

[Registration Number: NCT01939717]

Title and Abstract

1a Identification as a randomised trial in the title
A randomised controlled pilot trial to comparing Irish set dancing to usual care for people with Parkinson’s disease.

1b Structured summary of trial design, methods, results, and conclusions
A structured summary containing information regarding the trial design, methods, results and conclusions will be formatted once the trial is completed.

Introduction

2a Scientific background and explanation of rationale
Parkinson’s disease is a neurodegenerative disorder that affects approximately six million people worldwide (Baker and Graham 2004). People with Parkinson’s disease can present with movement disorders such as bradykinesia, akinesia, and rigidity. Postural instability is also frequently experienced by those with Parkinson’s disease and may be caused by a disruption in the release of neurotransmitters from the basal ganglia (Bronte-Stewart et al. 2002). Alterations in movement associated with Parkinson’s disease can result in reduced mobility and increased risk of falls (Morris 2000). Therapeutic physical rehabilitation is essential for those with Parkinson’s disease as medication is only partially effective in treating symptoms and may cause periods of dyskinesia (Rascol et al. 2000, Keus et al. 2004). The aims of physical rehabilitation are to optimise functional independence and increase quality of life for those with Parkinson’s disease (Keus et al. 2004). Irish set dancing is one type of rehabilitation strategy which may be beneficial for people with Parkinson’s disease as it involves dynamic balance training, continuous movement
initiation and cessation along with focusing of attention on body posture and foot placement (Murphy 2000, Volpe et al. 2013). Set dancing is also a partnered type of dance which may further enhance postural stability by providing tactile stimulation through touch (Hackney and Earhart 2010b).

Currently, only a small number of studies have investigated the feasibility of set dancing in Irish and Venetian populations with Parkinson’s disease (Volpe et al. 2013, Shanahan et al. 2015a) While the findings of these studies were positive and showed improvements in balance, motor impairment and quality of life after the set dancing intervention (Volpe et al. 2013, Shanahan et al. 2015a), further research is needed to determine the benefit of community-based set dancing for those with Parkinson’s disease and establish the appropriate methodology to use in larger international randomised controlled trials (RCTs). Therefore, this pilot RCT will:

(1) determine the feasibility of randomisation procedures, study design or acquiring essential resources for a larger trial
(2) investigate if recruitment rates and attrition levels are satisfactory for further trials
(3) explore the benefit of community-based set dancing for those with Parkinson’s disease in comparison to a usual care control group

2b Specific objectives or hypotheses

Objectives:

(1) To pilot the randomisation procedures and determine their feasibility
(2) To pilot the recruitment methods and determine their effectiveness for implementation in a larger trial
(3) To document issues relating to the methodology
(4) To monitor and document attrition levels from the study and reasons for discontinuing participation
(5) To compare functional exercise tolerance, balance, motor performance and quality of life in those with Parkinson’s disease before and after participating in set dancing classes, using the following validated outcome measures:
unified Parkinson’s disease rating scale subsection-3 (UPDRS-3), the mini-BESTest, the Parkinson’s disease questionnaire (PDQ-39) and the six-minute walk test

(6) To compare baseline and follow-up results for functional exercise tolerance, balance, motor performance and quality of life in those with Parkinson’s disease receiving usual care

(7) To compare functional exercise tolerance, balance, motor performance and quality of life in those with Parkinson’s disease participating in set dancing classes to those receiving usual care

Hypothesis:

As this is a pilot trial it is hypothesised that:

1. the randomisation procedures will be implemented correctly
2. the community-based set dancing intervention will be safe
3. the recruitment methods will be effective and enable the recruitment of the desired number of participants
4. set dancing will have an effect on functional exercise tolerance, balance, motor performance and quality of life in those who participate in ten weeks of set dancing classes compared to a usual care control group

Methods

3a Trial design: Description of trial design (such as parallel, factorial) including allocation ratio
A multi-centered pilot RCT design will be used for the proposed study. Participants will be randomly assigned to one of two groups using a sealed envelope system. One group will continue with their usual care and participate in a community-based set dancing class. The second group will act as a control group and continue to receive their usual care only. The dance and control group will have 50 participants each. The location of each centre is presented in Figure 1.
3b Trial design: Important changes to methods after trial commencement (such as eligibility criteria), with reasons
Any changes which will be made to the methods after the trial has commenced will be reported.

4a Participants: Eligibility criteria for participants
A total of 100 participants with Parkinson’s disease who meet the inclusion and exclusion criteria will be recruited from The Parkinson's Association of Ireland, Parkinson’s support groups and through consultant neurologists, the HSE Mid-West Parkinson’s clinical nurse specialist and physiotherapists. Members of these organisations and patients under the care of consultant neurologists, the HSE Mid-West Parkinson’s clinical nurse specialist and physiotherapists will be given flyers
about the study and those who may be interested may contact the main researcher and a talk will be arranged to outline the project further and to distribute patient information sheets. Participants may then contact the main researcher at a later date if they wish to participate.

Participants will be eligible to participate if they meet the following inclusion criteria:

- Have a diagnosis of idiopathic Parkinson’s disease (Hackney et al. 2007b, Marchant et al. 2010), stage 1-2.5 on the modified Hoeln and Yahr scale for staging of Parkinson’s disease (Batson 2010)
- Able to walk independently for three meters (Hackney et al. 2007a)
- Over 18 years of age
- Not pregnant
- Have access to a Digital Versatile Disc player and/or computer to allow them to participate in the home exercise programme

Participants will be excluded from the study if they have:

- a serious cardiovascular and/or pulmonary condition (Lodder et al. 2004)
- a neurological deficit other than Parkinson’s disease (Batson 2010, Marchant et al. 2010)
- evidence of a musculoskeletal problem (Duncan and Earhart 2012), contraindicating participation in exercise participation (Lodder et al. 2004)
- a cognitive or hearing problem which will affect their ability to follow instructions or hear the music (Batson 2010)
- participated in regular dance classes in the past six months (Marchant et al. 2010)

All those eligible will be required to give written informed consent before participating in the study. Letters will be sent to participants’ general practitioners to ensure that they know of no reason why their patient should not participate in this
study prior to participation. A letter will also be sent to participant’s consultant neurologists when they are recruited through Parkinson’s support agencies.

4b Participants: Settings and locations where the data were collected

This is a multi-centered pilot trial and the research will take place in suitable locations in the Limerick, Tipperary, Clare, Roscommon, Mayo, Laois and Dublin regions.

5 Interventions: The interventions for each group with sufficient details to allow replication, including how and when they were actually administered

Set Dancing Class:

Participants allocated to the set dancing group will take part in one, 1.5 hour set dancing class per week over a ten week period (Shanahan et al 2015b) in conjunction to continuing with their usual care, exercise habits and daily activities. Classes will take place in a suitable dance hall. The dance class will be led by a set dancing teacher who has previously taught set dancing in a clinical population or by health professionals who were also set dancing teachers. All set dancing teachers will receive training on the feasibility and safety of teaching set dancing to people with Parkinson’s disease from a chartered physiotherapist.

Participants will be encouraged to take rests as required and to inform the dance instructor if they feel unwell. During the dance class those with Parkinson’s disease will be partnered with an individual who does not have Parkinson’s disease (Hackney and Earhart 2010b). Spouses, care givers and family members will be invited to partner each participant with Parkinson’s disease during the class (Heiberger et al. 2011). This will ensure patient safety is maximised.

The dance class will start with a warm up. The aim of the warm up is to prepare the body for dance (Woods et al. 2007). Exercises to optimise joint range of motion (Hackney and Earhart 2010a, Heiberger et al. 2011), postural alignment and target the physiological systems (aerobic, muscular and neuromuscular) required for dance (Irvine et al. 2011) will be performed. Attentional focus will be placed on movement quality during all exercises to help enhance movement generation (Morris et al. 2011). Exercises will be performed in sitting and progressed to supported standing.
using the back of a chair and to unsupported standing in line with the participant’s abilities.

The main part of the class will involve participants learning various set dancing steps including the reel and hornpipe steps. Participants will then combine these steps with patterns of movement in a group formation to create a set. Sets from different regions of Ireland such as the Connemara Set, Kilfenora Set and Corofin Plain Set will be taught (Murphy 1995, Murphy 2009). The steps and sets thought will be aimed at treating Parkinson’s related movement disorders by focusing on foot placement, postural control and the correct timing of movement initiation and termination using rhythmical cues provided by the music (Morris 2000). The complexity of the dance material thought will be gradually progressed in line with the participants’ abilities (Marchant et al 2010).

The class will end with each couple practicing a gait pattern using music as an external cue (Hackney and Earhart 2009c). Gentle flexibility exercise will also be performed to optimise joint range of motion (Critchfield 2012).

Participants will be given a 20 minute dance-based home exercise programme to complete three times a week in addition to attending the dance classes. The aim of the home programme is to facilitate learning and increase weekly dance levels. The home programme will involve chair-based exercises to reduce falls risk and active practice of material taught in class to music. Participants will be instructed to mentally rehearse dance material to further facilitate learning during rest periods (Malouin et al. 2013). A standardised video interactive Digital Versatile Disc and Compact Disc, developed by a dance instructor (author) will also be given (Jovancevic et al. 2012). Adherence to the home programme will be monitored using a home exercise diary.

Participants in the dance group will complete a total of 150 minutes of dancing per week. This level of physical activity would meet the recommendations for physical activity and would be in line with the protocols of previous dance studies (Duncan and Earhart 2012, Foster et al. 2013).
The usual care group:
Usual care will involve participants continuing with their Parkinson’s and non-Parkinson’s medication and any other intervention which they normally receive. Thus, participants allocated to the usual care group will continue with their usual medication regime, activities of daily living and exercise habits.

After completion of the follow-up assessments participants in this group will be offered the set dancing intervention, however, they will not be obliged to attend the classes.

6a Outcomes: Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed

Primary outcome measure:
1. Feasibility of randomisation procedures
   This outcome will assess the implementation of randomisation and allocation procedures (Charlesworth et al. 2013, Tickle-Degnen 2013, Avery et al. 2014). Any issues affecting correct implementation of the procedures will be documented.

2. Resources
   This outcome will assess the availability and cost of personnel and building needed to implement study methodology. Issues regarding availability of personnel or buildings needed to implement study methodology will be documented (Tickle-Degnen 2013, Blandy et al. 2015).

3. Recruitment rates
   This outcome will assess the rate, duration and success of recruitment methods. This will enable recruitment rates for a larger trial to be estimated (Tickle-Degnen 2013). Recruitment methods will be considered successful and feasible is 100 participants are recruited in one year.
4. The willingness of participants to be randomised
This outcome will be assessed by monitoring the willingness of the participants to take part after been advised of their group allocation will be documented.

5. Attrition
This outcome will assess the dropout rate during the study. An attrition rate of $\leq$ 20% per group will be deemed acceptable (Centre for Evidence-based Medicine 2005).

6. Safety
This outcome will be assessed by monitoring and documenting adverse events during the intervention. The intervention will be considered safe if no adverse effects are reported.

7. Intervention adherence
This outcome will assess compliance with the dance intervention. The intervention will be considered successful if attendance at dance classes is $\geq$70% (Fielding et al. 2007) and no adverse effects are reported.

Secondary outcome measures:
1. UPDRS-3
UPDRS-3 is a motor subscale of the UPDRS (Fahn et al. 1987). It is a measure of disease severity (Hackney et al. 2007b). The motor subscale examines various motor impairments which are associated with Parkinson’s disease such as speech, tremor at rest, rigidity and gait (Heiberger et al. 2011). Higher scores indicate more severe disease stage. This is a disease specific measure which is valid (Hackney et al. 2007b) and reliable with an excellent Intra-Class Correlation Co-efficient for test re-test reliability (Siderowf et al. 2002) and intra-rater reliability (Metman et al. 2004).

2. PDQ-39
Health related quality of life will be assessed using the Parkinson’s Disease Questionnaire-39 (PDQ-39) (Marchant et al. 2010). This valid and reliable
questionnaire (Hackney and Earhart 2009b) assesses the impact of Parkinson’s disease in eight different areas including mobility, emotional well-being and communication. The summary index (PDQ-39 SI) provides an overall score of the impact of Parkinson’s on quality of life. Previous research has found that this measure that can detect changes in health related quality of life in response to interventions (Jenkinson et al. 1997).

3. Six-Minute Walk Test
The six-minute walk test will be used to assess functional exercise tolerance (Falvo and Earhart 2009). This test requires participants to walk along a pre-measured pathway for six minutes. This test is valid, reliable (Schenkman et al. 1997) and clinically applicable as it is simple to reproduce and reflects endurance needed for activities of daily living (Enright 2003). In previous studies, this test has detected changes in exercise tolerance in those with Parkinson’s disease who completed a dance intervention (Hackney and Earhart 2009a).

4. Mini-BESTest
The mini-BESTest provides a comprehensive assessment of balance in five different areas including dynamic balance, sensory orientation and postural responses (King et al. 2012). Research has found that this test can detect minor deficits in postural stability in those with Parkinson’s disease which may be overlooked in other balance tests. This measure is sensitive to changes in balance and has excellent inter-rater and test-retest reliability (Godi et al. 2013).

5. Exit Questionnaire
The exit questionnaire will assess participants’ satisfaction with the dance intervention at the end of the study. The questionnaire asks participants if they have noted improvements in different aspects of physical well-being, and allows feedback relating to the structure, material and enjoyment of the dance classes to be gathered. This questionnaire has previously been used in other studies investigating the benefit of dance for those with Parkinson’s disease (Hackney and Earhart 2009a, Hackney and Earhart 2010b).
Questionnaires to be used to gather demographic information:

1. PHASE

The PHASE will be used to identify the physical activity levels (Clemson et al. 2012) of the sample recruited in this study. This is a reliable tool (Washburn et al. 1993) and has been validated against physical activity measured via an accelerometer (Washburn and Ficker 1999). It’s also been shown to be significantly correlated with age, resting heart rate, grip and leg strength (Washburn et al. 1993) as well as VO2max, blood pressure and Berg Balance Scale scores (Washburn et al. 1999). This has been sued in previous studies carried out in those with Parkinson’s disease (Duncan and Earhart 2012).

Assessment:

Assessments will take place during the week preceding the start of the intervention period and within a week following the end of the intervention period (McKee and Hackney 2013). All assessments will be carried out by two blinded assessors who will be blinded to participants’ group allocation to ensure bias is not introduced into the results.

A standardised script will be used for all assessments (Hackney et al. 2007b). Where possible, participants will be assessed at the same time of day in all assessments to avoid fluctuations in performance (Hackney and Earhart 2009b). Participants will choose a testing time which best suits their needs. Participants will be instructed not to change their normal activities of daily living routine or their usual care unless advised by their practitioner. Participants will be instructed to inform the researcher if there are any changes made to their usual care over the trial period (Hackney and Earhart 2009b). If changes are made to a participant’s usual care or exercise regime over the trial period their data will be eliminated from the study to ensure results are accurate (Hackney and Earhart 2009b). In addition participants’ age, gender, stage of disease, year of diagnosis with Parkinson’s disease, usual care regime and past set dancing experience will be recorded.
6b Outcomes: Any changes to trial outcomes after the trial commenced, with reasons
Any changes in the outcome measures used in the study will be reported.

7a Sample size: How sample size was determined
In this pilot trial, it is necessary to estimate the expected rate of recruitment for a larger trial. Therefore, 100 participants, approximately 25% of the sample size required to power the larger trial (394 participants to detect a four point difference in the PDQ-39) will be recruited over a 12 month period in this study. The sample size for the larger RCT was determined by a statistician using statistical analysis of data from the feasibility (Shanahan et al. 2015a) study described in chapter 4 of this thesis.

7b Sample size: When applicable, explanation of any interim analyses and stopping guidelines
No interim analyses will be performed, however a feasibility study was carried out and no adverse effects were noted. Thus, it is expected that no adverse effects will be reported, however if any adverse effects from the intervention are reported the trial will be stopped if necessary.

8a Randomisation: Sequence generation: Method used to generate the random allocation sequence
The generation of the randomisation sequence will be performed separately for centre. This is necessary to ensure at least four people with Parkinson’s disease are allocated to the dance group in each centre. The following procedures will be used to generate the random sequence for each centre:

An individual blinded to the hypothesis of the study will prepare the desired number of envelopes for each centre. Half of the envelopes will inform participants that they are allocated to the set dancing group and half will inform participants that they are allocated to the usual care control group. An allocation form for each group will be placed consecutively into a sealed envelope. The envelopes will be placed in a secured box and then given to an independent mediator who will store the envelopes in a location which will not be disclosed to members of the research team. The
independent mediator will not be involved in the study and will be blinded to the hypothesis of the study. When a person is recruited to the study an envelope will be randomly selected by the independent mediator who will write the participant’s details on the envelope (Schulz and Grimes 2002).

8b Randomisation: Type of randomisation; details of any restriction (such as blocking and block size)

The randomisation procedure will be carried out using a sealed envelope system (Hesse et al. 2005). Fifty per cent of the envelopes will allocate participants to the set dancing group and 50% of the envelopes will allocate participants to the usual care group.

9 Allocation concealment mechanism: Mechanism used to implement the random allocation sequence (such as sequentially numbered containers) describing any steps taken to conceal the sequence until interventions were assigned

After the sealed envelopes have being prepared, an independent mediator will store them in a location which will not be disclosed to members of the research team. After baseline assessments have being completed, the independent mediator will give each participant their allocated envelope. Only the independent mediator will be present when each participant opens their envelope to ensure adequate concealment of group allocation. The independent mediator will record each participant’s group allocation in a log book. This log book will also be stored in an undisclosed location.

The independent mediator will assign a random identity code to each participant. This identity code will be used on all assessment sheets to ensure that the main researcher is blinded to group allocation. Only the assessors will be informed of each participant’s corresponding identity code to so that they can be written on all assessment sheets instead of participant’s name. However the assessors will remain blinded to group allocation.
10 Implementation: Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions

Individuals blinded to the hypothesis of the study will generate the random allocation and implement the random allocation procedure.

11a Blinding: If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how

Participants will be blinded to the hypothesis of the study but will not be blinded to the intervention as they will be either participating in a dance class or not. However, assessors will be blinded to who will be receiving the intervention.

The assessors will be blinded to group allocation.

11b Blinding: If relevant, description of the similarity of interventions

Participants will be blinded to the hypothesis of the study. A similarity between both groups will be that all participants will continue their usual care.

12a Statistical methods: Statistical methods used to compare groups for primary and secondary outcomes

As discussed above, the primary outcome for this study is feasibility. Dimensions of feasibility will be summarised using percentages, means and standard deviation or non-parametric equivalents. For secondary outcomes, intragroup and between-group comparisons will be done using appropriate parametric tests such as t-tests or non-parametric tests, depending on the distribution of the data. Intention-to-treat analysis will be done as appropriate. Descriptive statistics will be done to give a descriptive account of participants (age, gender, stage of disease, duration of Parkinson’s disease). The most recent version of SPSS will be used to analyse data.

12b Statistical methods: Methods for additional analyses, such as subgroup analyses and adjusted analyses

No sub analyses are anticipated. However, any if sub group analyses are warranted, the methods will be adequately reported.
References


Hackney, M. E. and Earhart, G. M. (2010a) 'Effects of dance on balance and gait in severe Parkinson disease: a case study', *Disability and Rehabilitation*, 32(8), 679-84.


Heiberger, L., Maurer, C., Amtage, F., Mendez-Balbuena, I., Schulte-Monting, J., Hepp-Reymond, M. C. and Kristeva, R. (2011) 'Impact of a weekly dance class on the functional mobility and on the quality of life of individuals with...


in patients with early Parkinson's disease: results from a multicenter clinical trial', Movement Disorders, 17(4), 758-763.


Appendix H: Flyer for Randomised Controlled Pilot Trial

A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease
EHSREC Approval Number: 2013_04_41_EHS

Flyer

Researchers at the University of Limerick are looking for people with Parkinson’s disease to participate in a study investigating the comparing set dancing to usual care

What do I have to do?:
If you take part in this study you will be randomly assigned to one of two groups:

1. One group will take part in 10 weeks of set dancing classes and continue with their usual care.
2. The other group will continue with the usual care only for 10 weeks and will then participate in set dancing classes.

Why get involved?

- The results of this study would help to determine the benefit of set dancing for those with Parkinson’s disease and inform rehabilitation strategies.
- You will also get an opportunity to take part in regular dance classes, free of charge which may help to improve aspects of your physical wellbeing and quality of life.

Want to get involved?
If you are interested in taking part and would like further information please contact a member of the research team:
Joanne Shanahan, MISCP, Set Dancing Teacher, PhD Candidate, Department of Clinical Therapies, Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: Joanne.Shanahan@ul.ie
Dr. Amanda Clifford: Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: Amanda.Clifford@ul.ie. Tel: 061 234118
Dr. Orfhlaith Ní Bhriain: Irish World Academy of Music and Dance, University of Limerick. Email: Orfhlaith.NiBhriain@ul.ie Tel: 061 20 2470
Appendix I: Patient Information Leaflet for Randomised Controlled Pilot Trial

A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease
EHSREC Approval Number: 2013_04_41_EHS

Patient Information Leaflet

Introduction
The aim of this study is to conduct a pilot trial to determine the feasibility of a randomised controlled study design and to compare the effects of set dancing to usual care for those with Parkinson’s disease in Ireland.

Procedures
Participants who agree to take part in the study will be assigned to one of two groups.

1. One group will take part in set dancing classes and continue with their usual care.
2. The other group will continue with their usual care only and will not attend set dancing classes.

As we aim to explore the effect of set dancing as an addition to usual care, no additional exercise or dancing classes should be taken up during the research study. In addition the main researcher must be informed if your usual medication regime changes during the study.

All participants should be aware that if you are assigned to the group who does not attend set dancing classes during the study you will be invited to attend set dancing classes once the study is finished.
The group which you are allocated to will be done on a random basis using sealed envelopes. You must not reveal your group allocation to the investigators to ensure that results are analysed independently.

You and your main care giver will also be asked to attend the University of Limerick for a short assessment before the immediately after the set dancing classes. These assessments will take approximately one hour to complete.

The set dancing classes will run for ten weeks and will take place in the University of Limerick. The classes will last an hour and a half and will be taught by a set dancing teacher who has previously taught set dancing in a clinical population or by health professionals who were also set dancing teachers. All set dancing teachers will have received training on the feasibility and safety of teaching set dancing to people with Parkinson’s disease from a chartered physiotherapist. You can bring a dance partner to the class. This can be a family member, spouse or carer. A home dance exercise programme will also be given to you to take part in.

**Benefits**

Set dancing may help to improve your walking and enable you to move easier so that daily tasks can be performed easier. Your quality of life may also be improved by participating in set dancing classes.

**Risks.**

There are no serious risks associated with this study. There is a minor risk of slipping while dancing, however, this risk is reduced as you will be dancing with a dance partner at all times.

Those unaccustomed to exercise may experience some muscle soreness. However, a gentle warm up and cool-down will be performed at every class to allow the body to gradually adjust to exercise. There will also be frequent rest periods during the dance class to ensure that muscles do not get fatigued. You are also free to sit and rest at any time during the class if you need to.
Exclusion from participation
You will not be able to participate in this study if you have:

- a serious heart and/or lung condition
- a neurological deficit other than Parkinson’s
- Evidence of a musculoskeletal problem contraindicating participation in exercise participation
- a cognitive or hearing problem which affect your ability to follow instructions or hear the music
- participated in a regular dance class in the past six months

You will be able to participate if you:

- have a diagnosis of Parkinson’s disease, stage 1-2.5 on the modified Hoehn and Yahr scale for staging of Parkinson’s disease
- are showing a clear benefit from your anti-Parkinson medication
- are able to walk independently for three metres
- are not pregnant
- are over 18 year of age
- have access to a computer to allow you to participate in the home exercise programme.

Alternate Treatment
This study is investigating the feasibility of a randomised controlled study design and comparing the effects of set dancing to usual care for people with Parkinson’s disease. This study does not offer an alternate treatment if you do not wish to attend set dancing classes. However, you are not obliged to participate in the study if you do not wish to.

Confidentiality
All personal information is confidential. Your name will not be attached to any data. All participants’ names will be written in a log book and matched with an
identification code. The log book will be stored in a secure location. The identification code will be used on all assessment sheets. The anonymised information gathered will be analysed in appropriate statistical tests and presented as the results of the study. All data will be stored in a locked cabinet in the office of the main researcher.

**Permission**
You will be asked to disclose the following information to the main researcher:

- The duration of your condition
- The type and dosage of your anti-Parkinson’s medication
- Your general practitioners and consultant neurologist’s name and address so that they can be informed that you are participating in the study

**Compensation**
There will be no financial reward for participating in this study.

**Voluntary Participation and Stopping the Study**
You are not obliged to participate in this study you may leave the study at any time if you wish without giving any reason. If for any reason you and other participants feel that the intervention is having adverse effects on your health or quality of life the study will be stopped.

**Further Information**
If you have any further queries, please contact one of the research team:
Joanne Shanahan: PhD Research Student
Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick.
Email: Joanne.Shanahane@ul.ie

Dr. Amanda Clifford:
Department of Clinical Therapies,
Faculty of Education and Health Sciences, University of Limerick.
Email: Amanda.Clifford@ul.ie, Phone: 061 234118
Complaint Procedure

If you have any concerns or complaints about this study and would like to contact someone independent, you may contact The Chairman, Education and Health Sciences, Research Ethics Committee, EHS Faculty Office, University of Limerick. Tel (061) 234101 Email: ehsresearchethics@ul.ie
Appendix J: Informed Consent Form for Randomised Controlled Pilot Trial

A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease

EHSREC Approval Number: 2013_04_41_EHS

Informed Consent Form

Please tick the box if you agree with the statement:

<table>
<thead>
<tr>
<th>Statement</th>
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<tr>
<td>I have read and fully understand the subject information sheet.</td>
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<tr>
<td>I understand that my participation is voluntary and that I can withdraw from the project at any stage without giving any reason</td>
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<tr>
<td>I agree to disclose the relevant medical information required for the study to the main researcher as described in the patient information sheet.</td>
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<tr>
<td>I give permission to the research team to inform my general practitioner and consultant neurologist that I am participating in the study</td>
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<tr>
<td>I understand that I must inform the research team immediately of any adverse effects experienced due to my participation in the study</td>
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<tr>
<td>I am aware that my results will be kept confidential.</td>
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<tr>
<td>I agree to participate in this study.</td>
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</table>

Signature: ___________________________  Date: __________

Printed: ___________________________  Date: __________

Witness Signature: _______________________  Date: __________

Witness Printed: ___________________________  Date: __________

Investigator’s Signature: ___________________________  Date: __________

Investigator’s Printed: ___________________________  Date: __________
Appendix K: Letter to General Practitioner for Randomised Controlled Pilot Trial

A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease
EHSREC Approval Number: 2013_04_41_EHS

Dear Dr________________

(Patient’s name) has volunteered to participate in a research study entitled “A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease”. This study is being carried out by researchers at the University of Limerick in collaboration with Prof Meg Morris at LaTrobe University in Melbourne, Australia and Dr Danielle at St John of God Hospital Parkinson's Centre in Venice, Italy.

The aim of this study is to conduct a pilot trial to determine the feasibility of a randomised controlled study design and to compare the effects of set dancing to usual care for those with Parkinson’s disease in Ireland.

All participants will undergo assessments of functional exercise tolerance, balance, motor performance and quality of life. Those randomised to the intervention group will also participate in set dancing classes for ten weeks.

To ensure eligibility to participate in this study all volunteers will be reviewed by clinician and the main researcher. In addition as (patient’s name) general practitioner could you please inform me before (date) if you know of a reason why your patient should not participate in this study. If I do not receive any correspondence by the
(date), (patient’s name) will be enrolled in the study. I have listed the inclusion and exclusion criteria below.

Participants will be eligible to participate if they meet the following inclusion criteria:

- Have a diagnosis of idiopathic Parkinson’s disease, stage 1-2.5 on the modified Hoel and Yahr scale for staging of Parkinson’s disease
- Able to walk independently for three meters
- Not pregnant
- Over 18 year of age
- Have access to a computer to allow them to participate in the home exercise programme

Participants will be excluded from the study if they have:

- a serious cardiovascular and/or pulmonary condition
- a neurological deficit other than Parkinson’s disease
- evidence of a musculoskeletal problem contraindicating participation in exercise participation
- a cognitive or hearing problem which will effect their ability to follow instructions or hear the music
- participated regularly in a dance class in the past six months

I have enclosed a copy of the patient information leaflet which outlines the study in more detail. Please do not hesitate to contact me or any member of the research team if you have any queries regarding this study.

Yours sincerely

_______________________
Joanne Shanahan, MISCP
PhD. Candidate,
Department of Clinical Therapies,
Faculty of Education and Health Sciences,
University of Limerick,
Limerick
Email: Joanne.Shanahan@ul.ie

Dr. Amanda Clifford, MISCP
Department of Clinical Therapies,
Faculty of Education and Health Sciences,
University of Limerick,
Limerick,
061234118
Email: Amanda.Clifford@ul.ie

Dr. Orfhlaith Ni Bhriain,
Irish World Academy of Music and Dance,
University of Limerick,
061 20 2470
E-mail: Orfhlaith.NiBhriain@ul.ie
Appendix L: Letter to Consultant Neurologist for Randomised Controlled Pilot Trial

Dear Dr________________

(Patient's name) has volunteered to participate in a research study entitled “A Randomised Controlled Pilot Trial Comparing Irish Set Dancing to Usual Care for People with Parkinson’s Disease”. This study is being carried out by researchers at the University of Limerick in collaboration with Prof Meg Morris at LaTrobe University in Melbourne, Australia and Dr Danielle at St John of God Hospital Parkinson's Centre in Venice, Italy.

The aim of this study is to conduct a pilot trial to determine the feasibility of a randomised controlled study design and to compare the effects of set dancing to usual care for those with Parkinson’s disease in Ireland.

All participants will undergo assessments of functional exercise tolerance, balance, motor performance and quality of life. Those randomised to the intervention group will also participate in set dancing classes for ten weeks.

To ensure eligibility to participate in this study all volunteers will be reviewed by clinician and the main researcher. In addition as (patient’s name) consultant neurologist could you please inform me before (date) if you know of a reason why your patient should not participate in this study. If I do not receive any
correspondence by the (date), (patient’s name) be enrolled in the study. I have listed the inclusion and exclusion criteria below.

Participants will be eligible to participate if they meet the following inclusion criteria:

- Have a diagnosis of idiopathic Parkinson’s disease, stage 1-2.5 on the modified Hoehn and Yahr scale for staging of Parkinson’s disease
- Able to walk independently for three meters
- Not pregnant
- Over 18 year of age
- Have access to a computer to allow them to participate in the home exercise programme

Participants will be excluded from the study if they have:

- a serious cardiovascular and/or pulmonary condition
- a neurological deficit other than Parkinson’s disease
- evidence of a musculoskeletal problem contraindicating participation in exercise participation
- a cognitive or hearing problem which will effect their ability to follow instructions or hear the music
- participated regularly in a dance class in the past six months

I have enclosed a copy of the patient information leaflet which outlines the study in more detail. Please do not hesitate to contact me or any member of the research team if you have any queries regarding this study.

Yours sincerely

_______________________
Joanne Shanahan, MISCP  
PhD. Candidate,  
Department of Clinical Therapies,  
Faculty of Education and Health Sciences,  
University of Limerick,  
Limerick  
Email: Joanne.Shanahan@ul.ie  

Dr. Amanda Clifford, MISCP  
Department of Clinical Therapies,  
Faculty of Education and Health Sciences,  
University of Limerick,  
Limerick,  
061234118  
Email: Amanda.Clifford@ul.ie

Dr. Orfhlaith Ní Bhriain,  
Irish World Academy of Music and Dance,  
University of Limerick,  
061 20 2470  
E-mail: Orfhlaith.NiBhriain@ul.ie
Appendix M: Home Exercise Diary for Randomised Controlled Pilot Trial

A study to determine the feasibility of set dancing for people with Parkinson’s disease in Ireland

Name:

**Home Dance Diary**

Please fill in below how much time you spend completing your home exercise programme. Try to do three 20 minute sessions each week.

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Appendix N: Patient Information Leaflet for Nominal Group Technique for Set Dancing Teachers

Development of an Educational Resource on Parkinson’s disease for Irish Set Dancing Teachers

EHSREC Approval Number: 2013_04_41_EHS

Patient Information Leaflet

Introduction
The aim of this study is to develop an educational resource for set dancing teachers on Parkinson’s disease.

What will you have to do as part of the study?
All those who agree to take part will be asked to sign an informed consent form. Following this, a group discussion will be held to:

1) identify information gaps that you and other participants in the group have in relation to teaching set dancing to people with Parkinson’s disease
2) identify other information Irish set dancing teachers would like included in an educational resource to facilitate teaching set dancing to people with Parkinson’s disease

During this discussion you will be asked to discuss and anonymously write down suggestions/ideas you have in relation to the two topic areas outlined above.

In attendance at this group discussion will be a chairperson and approximately 4-6 set dancing teachers. All opinions are equally valued and will help inform the
development of this educational resource. The group discussion will last approximately 40 minutes. The location and date/time of the discussion will be arranged to suit those who volunteer. At the end of the discussion you will be asked to place your written anonymised topics in a sealed box. All the information collected will be analysed by the chairperson and other members of the research team in order to identify the most commonly reported topics participants feel need to be included in the educational resource.

When a draft version of the educational resource has been prepared, two participants will be randomly selected and invited to read and feedback on the resource. This will ensure the content of the educational resource addresses topics developed during the group discussion. A copy of this draft version will be emailed to participants randomly selected to read the educational resource. You will be asked to give your email address to the chairperson before you leave the group discussion.

**What are the benefits?**
If you take part in this study you will help identify information most relevant to include in this educational resource. This may help facilitate you and other set dancing teachers when teaching set dancing to people with Parkinson’s disease.

**What are the risks?**
There are no risks associated with this study.

**Alternate Treatment**
This study does not offer an alternate treatment if you do not wish take part in the group discussion. However, you are not obliged to participate in the study if you do not wish to.

**Confidentiality**
All personal information collected will be written in a log book, kept confidential and stored in a secure location. The data collected during the group discussion will be anonymised. The anonymised information gathered will be analysed using appropriate methods and used to inform the content of the educational resource. All
personal information and data will be stored in a locked cabinet in the office of the main researcher.

**Permission**
You will be asked to sign an informed consent form before taking part and to disclose your email address to the chairperson if you would like to receive a draft copy of the educational resource.

**Compensation**
There will be no financial reward for participating in this study.

**Voluntary Participation and Stopping the Study**
You are not obliged to participate in this study you may leave the study at any time.

**Further Information**
If you have any further queries, please contact one of the research team:

- **Joanne Shanahan:** PhD Researcher, Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: Joanne.Shanahan@ul.ie
- **Dr. Amanda Clifford,** Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: Amanda.Clifford@ul.ie, Phone: 061 234118
- **Dr. Orfhlaith Ni Bhriain,** Irish World Academy of Music and Dance, University of Limerick. Email: Orfhlaith.NiBhriain@ul.ie, Phone 061 202470

**Complaint Procedure**
*This research study has received Ethics approval from the Education and Health Sciences Research Ethics Committee (quote approval number). If you have any concerns about this study and wish to contact someone independent you may contact, Chairman Education and Health Sciences Research Ethics Committee EHS Faculty Office, University of Limerick, Tel: (061) 234101. Email: ehsresearchethics@ul.ie*
Appendix O: Patient Information Leaflet for Nominal Group Technique for People with Parkinson’s Disease

Development of an Educational Resource on Parkinson’s disease for Irish Set Dancing Teachers
EHSREC Approval Number: 2013_04_41_EHS

Patient Information Leaflet

Introduction
The aim of this study is to develop an educational resource for set dancing teachers on Parkinson’s disease.

What will you have to do as part of the study?
All those who agree to take part will be asked to sign an informed consent form. Following this, a group discussion will be held to:

1) identify the needs of people with Parkinson’s disease in relation to the structure of a set dancing class
2) identify the knowledge that people with Parkinson’s disease would like set dancing teachers to know about their condition

During this discussion you will be asked to discuss and anonymously write down suggestions/ideas you have in relation to the two topic areas outlined above.

In attendance at this group discussion will be a chairperson and approximately 4-6 people with Parkinson’s disease who have participated in set dancing classes. All opinions are equally valued and will help inform the development of this educational resource. The group discussion will last approximately 40 minutes. The location and
date/time of the discussion will be arranged to suit those who volunteer. At the end of the discussion you will be asked to place your written anonymised topics in a sealed box. All the information collected will be analysed by the chairperson and other members of the research team in order to identify the most commonly reported topics participants feel need to be included in the educational resource.

When a draft version of the educational resource has been prepared, two participants will be randomly selected and invited to read and feedback on the resource. This will ensure the content of the educational resource addresses topics developed during the group discussion. A copy of this draft version will be emailed to participants randomly selected to read the educational resource. You will be asked to give your email address to the chairperson before you leave the group discussion.

**What are the benefits?**

If you take part in this study you will help identify information most relevant to include in this educational resource. This may help facilitate set dancing teachers when teaching set dancing to people with Parkinson’s disease.

**What are the risks?**

There are no risks associated with this study.

**Alternate Treatment**

This study does not offer an alternate treatment if you do not wish to take part in the group discussion. However, you are not obliged to participate in the study if you do not wish to.

**Confidentiality**

All personal information collected will be written in a log book, kept confidential and stored in a secure location. The data collected during the group discussion will be anonymised. The anonymised information gathered will be analysed using appropriate methods and used to inform the content of the educational resource. All personal information and data will be stored in a locked cabinet in the office of the main researcher.
Permission

You will be asked to sign an informed consent form before taking part and to disclose your email address to the chairperson if you would like to receive a draft copy of the educational resource.

Compensation

There will be no financial reward for participating in this study.

Voluntary Participation and Stopping the Study

You are not obliged to participate in this study you may leave the study at any time.

Further Information

If you have any further queries, please contact one of the research team:

Joanne Shanahan: PhD Researcher, Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: 0839264@studentmail.ul.ie

Dr. Amanda Clifford, Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick. Email: Amanda.Clifford@ul.ie Phone: 061 234118

Dr. Orfhlaith Ni Bhriain, Irish World Academy of Music and Dance, University of Limerick. Email: Orfhlaith.NiBhriain@ul.ie Phone 061 202470

Complaint Procedure

This research study has received Ethics approval from the Education and Health Sciences Research Ethics Committee (quote approval number). If you have any concerns about this study and wish to contact someone independent you may contact, Chairman Education and Health Sciences Research Ethics Committee EHS Faculty Office, University of Limerick, Tel: (061) 234101. Email: ehsresearchethics@ul.ie
Appendix P: Informed Consent Form for Nominal Group Technique

Development of an Educational Resource on Parkinson’s disease for Irish Set Dancing Teachers
EHSREC Approval Number: 2013_04_41_EHS

**Informed Consent Form**

Please tick the box if you agree with the statement:

<table>
<thead>
<tr>
<th>Statement</th>
<th></th>
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<tr>
<td>I have read and fully understand the subject information sheet.</td>
<td></td>
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<tr>
<td>I understand that my participation is voluntary and that I can withdraw from the project at any stage without giving any reason</td>
<td></td>
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<tr>
<td>I am aware that all personal information collected will be kept confidential and that all data collected during the group discussion is anonymised.</td>
<td></td>
</tr>
<tr>
<td>I agree to participate in this study.</td>
<td></td>
</tr>
</tbody>
</table>

Signature: __________________________ Date:________

Witness Signature: __________________________ Date:________

Investigator’s Signature: __________________________ Date:________