Lesley University DigitalCommons@Lesley

Expressive Therapies Capstone Theses

Graduate School of Arts and Social Sciences (GSASS)

Spring 5-18-2019

Movement and Support as Treatment for Parkinson's Disease: A Literature Review

Sara K. Schmidt Lesley University, sschmid3@lesley.edu

Follow this and additional works at: https://digitalcommons.lesley.edu/expressive_theses

Part of the Social and Behavioral Sciences Commons

Recommended Citation

Schmidt, Sara K., "Movement and Support as Treatment for Parkinson's Disease: A Literature Review" (2019). *Expressive Therapies Capstone Theses*. 183. https://digitalcommons.lesley.edu/expressive_theses/183

This Thesis is brought to you for free and open access by the Graduate School of Arts and Social Sciences (GSASS) at DigitalCommons@Lesley. It has been accepted for inclusion in Expressive Therapies Capstone Theses by an authorized administrator of DigitalCommons@Lesley. For more information, please contact digitalcommons@lesley.edu, cvrattos@lesley.edu.

Movement and Support as Treatment for Parkinson's Disease: A Literature Review

Capstone Thesis

Lesley University

05/03/2019

Sara Schmidt

Dance/Movement Therapy

Vivien Marcow Speiser

Abstract

The purpose of this literature review is to discuss the benefit of support groups and dance classes for individuals living with Parkinson's Disease (PD). Questions for consideration in this literature review include looking at the possible added benefit of combining support and movement into one group. This writer will present the literature on the benefits of dance classes for individuals living with Parkinson's Disease and the literature on the benefits of support groups. This writer will then investigate if the potential benefits in a combined group are similar or the same as in separate support groups or dance classes. This writer will discuss data collected from a group I created at a skilled nursing facility for residents with Parkinson's Disease that was a combined movement and support group. The bias of this writer is that combing movement and support will provide an added measure of group cohesion and an increased feeling of support from the group with a decreased feeling of isolation.

Keywords: Parkinson's Disease, Movement, Support Groups, Dance Therapy

Movement and Support as Treatment for Parkinson's Disease: A Literature Review

The purpose of this thesis is to examine Parkinson's disease (PD) with specific focus on support groups and dance classes. My interest in examining the benefits of dance classes and support groups as another form of treatment for people living with PD is to discover the possible added benefit of combining support and movement into one group. Questions for consideration include, but are not limited to, whether combining support and movement into one group offers the same level of benefit as separate support groups and dance classes. Specific factors that will be explored as benefits of dance and support are quality of life, improved ability to perform daily activities, decreased isolation, and the reported impact of support and dance on mood and emotional well-being.

Parkinson's disease is reported as the second most common neurodegenerative condition next to Alzheimer's disease (Rajesh, 2009). Parkinson's disease (PD) is a neurodegenerative disorder that affects the nervous system (Weiner, Shulman, & Lang, 2007). Parkinson's disease progresses slowly over time and symptoms vary from person to person. PD impacts and degenerates cells in the brain called the substantia nigra, when these cells degenerate, it leads to a decrease in the brain's ability to tell the body to perform certain movements, which leads to common motor symptoms associated with PD. Common motor symptoms associated with PD are tremors, gait and balance difficulty, and rigidity in the limbs. Non-motor symptoms of PD include cognitive impairment, fatigue, sleep disorders, anxiety, depression, and hallucinations and delusions, to name a few.

The organization of this paper will include a look at the benefits of dance classes for people living with PD, followed by an exploration of the benefits of attending a support group

for people living with PD. The final section will involve a discussion about the possible benefit of combing support and movement by using data this writer gathered from a combined support and movement group that was started for the residents at a skilled nursing facility with a diagnosis of PD. The limitations of this paper include a bias that movement and support will provide a more comprehensive support. There is also a need for community engagement in implementing a movement and support group within local PD support groups with data gathered in the form of surveys and interviews.

The anticipated outcome of this literature review is to gain insight into how combining movement and support can provide an added benefit and be an additional form of treatment for individuals living with PD. My bias is that combining movement and support into one group will provide an added measure of group cohesion and an increased feeling of support, with a decreased feeling of isolation. In my experience as a volunteer at a Parkinson's dance class, individuals who attended the dance classe reported a decreased feeling of isolation and increased support. Each week the attendees in the class would gather to share how their week went, struggles they may have had, and adventures they had gone on before beginning to dance and move togethers (Personal Communication, June 2016).

Dance and movement impact the overall physical and emotional health of individuals living with PD. Support groups provide people living with PD the opportunity to share thoughts, emotions, and fears about their disease, discuss available treatments, and to talk and share with people who have the same diagnosis and a deeper understanding of their experience (Delisle et al., 2017). Further research is needed on whether combining the support group experience with dance and movement could provide an increased measure of support. Combining support groups and movement groups has the potential to provide an atmosphere of camaraderie and feelings of friendship and connection for a greater number of people.

Literature Review

Impact of Dance

Parkinson's Disease (PD) affects and impacts each person differently. One of the most commone non-motor symptoms of PD is cognitive impairment, which impacts a person's ability to remember basic everyday things like where they put their keys, the name of a friend or loved one, or where they live, to name only a few. PD can impair a person's ability to pay attention and focus on daily tasks, some examples of this are having trouble making food, driving a car, taking a shower, or making a grocery list (Hashimoto, Takabatake, Miyaguchi, Nakanishi, & Naitou, 2015). PD has been proven to have a negative impact on mood and can lead to depression and a lack of desire to engage in regular activities, or apathy. In a qualitative study conducted by Hashimoto et al., they investigated the impact of dance and movement on the cognitive, motor, and mental symptoms of individuals living with PD. They performed a control study with one group continuing their regular daily activities as normal. The other two groups were divided into a dance group and an exercise group. Participants were randomly selected to be in each group and were administer a pre-test 1 week before their 12 sessions began and a posttest within one week after the end of the 12 weeks. The outcomes of the study indicated that the individuals who participated in the dance group showed improvements in all the areas being investigated including, cognition, motor function, apathy and depression. Individuals in the control group showed improvement in only one motor test and scores dropped on the overall Parkinson's symptoms scale. Participants in the control group and the exercise group did not report

improvement in depression and apathy, only the dance group saw improvement in the area of mood.

There is significant research on the impact of movement and exercise on neuroplasticity and how the brain can begin to repair itself (Sharp & Hewitt, 2014). Research on the impact of exercise on the enhancement of neuroplasticity in PD, suggests five neccessary factors. The five key factors suggest that activity helps to make the most of synaptic plasticity, engaging in complex activity or exercise promotes improved "structural adaptation", exercise and activities illicit increased dopamine and increases learning ability, dopamine neurons respond positively to exercise and to inactivity due to lack of movement or exercise (p. 446). Important to note that the writers consider that dance and exercise are beneficial only if they are done on a regular basis, usually 2-3 times a week for an extended period of at least 4-12 weeks. In their review of research on the impact of dance on PD, Sharp and Hewitt discovered that if done over an extended length of time, dance improves gait and balance, improves mood, and has a better effect on people living with PD compared with other interventions or no intervention. Movement and dance that involve certain rhythms like Tango, engage parts of the brain that increase serotonin, which leads to an overall sense of feeling better. In dance, a person has to attune to certain cues, they may be auditory like music, or visual in the form of a partner or the group moving (Earhart, 2009). The value of these cues for someone with PD is that the cues allow the brain to bypass the damaged parts and utilize other pathways. Music cues can facilitate movement and research shows auditory cues can even improve walking ability and performance in people with PD. Common among many studies on dance vs other interventions, is individuals who participate in dance classes as intervention tend to continue to engage in the activity even

after the completion of the study, which demonstrates a possibility for long-term impact on improved PD symptoms and quality of life.

In a quantitative study by McRae et al. (2018), the long-term impact of Dance for PD®, DfPD, on self-efficacy, quality of life, and confidence in the ability to perform daily living activities outside of class were assessed. The study was done using survey questions created to evaluate reported benefits of regularly attending a DfPD class. The survey asked questions about the impact of regularly attending a DfPD on daily living activities, self-efficacy, and quality of life. The survey was administered to individuals from four well-established DfPD classes in New York City. The results of the study found that 98% of participants reported that attending a DfPD class improves how they feel and 42% reported that they feel the benefits of the class for days following the class. The connection between self-efficacy and quality of life is one that has not been as investigated and this study implies that the connection and impact of the two should be further investigated. The results of this study provide insight into the benefits of using dance and the expressive therapies in providing a space for individuals with PD to improve strength and balance. Individuals also reported improved quality of life and improvement in daily activities from use of techniques learned in dance class. The results of this study reveal that while dance provides a space to learn, engage in social interactions, and develop new skills during class, it also provides lasting benefits outside of the class that filter into daily living. Skills and techniques learned in a dance class can help improve the ability to perform daily tasks like getting out of bed, washing dishes, and moving around the home.

In a qualitative study conducted by Ashburn et al., (2015), the overall benefit of dance as an appropriate intervention for individuals living with PD was evaluated. Individuals living with PD who were part of the study, participated twice a week for 10 weeks in a dance class that included ballroom dance and Latin American dances. The interviews were conducted within a month of the end of the class. The interviews sought to understand the participants views about where the class was held and accessibility, any challenges they faced during the class, reported impact of the class on mobility, and their interest in continuing to dance or attend dance classes. The responses to the survey found that individuals who participated in the program appreciated having assistance getting to the studio. Participants reported movement obstacles during the class were, struggling with turning, keeping up with timing of music, overall coordination during movement, and the challenges of remembering the steps to the dances. The overall response to the class was a feeling of achievement, enjoyment, and building rewarding social interactions with others in the class. All the participants reported having a desire and interest in continuing to take dance classes. The conclusion of the study was that dance is an appropriate intervention for individuals living with PD.

In a mixed methods qualitative study conducted by Houston and McGill (2013), they examined the benefits of attending a dance class for people with PD. The English National Ballet hosted classes for individuals with a diagnosis of PD over a 12-week period. The study involved filming each class for further assessment of movement progress, beyond individual report by participants. There were 24 individuals who volunteered to participate in the study. As a mixed methods study, all 24 participants were included in filming for the project, 14 of them were interviewed, 4 people chose to keep diaries of their experience, and 6 participants did the PD balance and posture test. There was a quantitative component that included 6 total volunteers to answer questions. To better understand why the volunteers were choosing to take the dance class, they were interviewed individually before, during, and after the project. The interview questions were structured but allowed for individuals to answer based on their own experience about their

life with PD. The researchers used the video footage from the classes and Laban Movement Analysis to assess the efforts used by participants in their movements. The videos provided insight into the physical progress made over the 12 weeks of the class. Assessments based on the video recordings allowed the researchers to see an increase in the ability of participants to walk in time to music and lengthen their strides, a decrease in rigidity, increased rotation in the spine, and increased body awareness. Self-reports via interviews after the project reflected a decrease in loneliness and increased overall well-being.

In the discussion section of the study, researchers reflect on the value of journaling by participants and the downside of journal keeping. The benefit to having individual participants keep journals is that it provided useful insight into the day to day life of participants. The limitations to participants keeping diaries are that people may not be completely forthcoming or may censor what they say to make it what they think the researcher may want them to say (Houston & McGill).

Individual reports after the 12-week class reflected that participants felt like the dance class was a better place to get to know people than a Parkinson's Support Group (Houston & McGill). This self-reported information from participants provides a nugget to hold onto as a possible answer in understanding the potential benefits of combining dance and support into one group. Combining the two could provide the emotional support of a support group and the social support and interaction that come from dancing and moving together. From the gathered data individuals reported that:

The social interactions created by attending the group provided another reason to continue to attend and stay in the class. These interactions played a crucial role in allowing participants to foster relationships, have fun together, find out about how others were coping with their condition, and to gain confidence in moving with others with similar challenges (p.16).

Moving together allows people to support and lift each other in a very real way physically and emotionally. Movement provides an opportunity for group members to focus on what their body can to do instead of what they are no longer able to do, providing a sense of empowerment and resilience. Moving together also provides a common goal for the group to work toward. In my experience as a volunteer at a dance class for PD, individuals who attended the dance class reported a decreased feeling of isolation and increased sense of community. An important consideration for combing movement and support is to determine whether there is an added measure of cohesion that can be gained by creating a setting where the sharing of personal struggles and successes are paired with sharing movement together.

Impact of Support Groups

Support groups have proven to be a valuable resource for people living with chronic illness. Support groups are perceived as providing benefits that include, but are not limited to, being able to interact with people who share a similar diagnosis or experience, space to learn more about the disease and treatments that are available, emotional support, being able to openly talk about fears associated with the disease, stresses or other feelings associated with the disease, developing coping skills, feeling hopeful about the future and empowered with knowledge, and a place where patients feel like they are advocating to improve healthcare for others with the disease (Delisle et al., 2016).

Support groups have been linked to long-term health outcomes that include better immune functionality and reduced mortality (Hogan, B., Wolfgang, L., Bahman, N., 2001).

Hogan et al. define three types of support that are gained from social support groups. Emotional support comes in the form of expression of caring and concern in verbal and nonverbal forms from friends and family and aids in reducing stress, increasing self-esteem, and providing patients the ability to express feelings and emotions. Informational support comes from the information that is provided by caretakers and providers about management and treatment, which helps to enhance the individuals sense of control by decreasing confusion about the diagnosis and providing possible coping strategies to manage difficulties that might arise. Instrumental support is the third type of support and provides support in the form of material goods that include access to transportation, financial assistance, or physical assistance, which helps to alleviate a sense of loss or feelings of loss of control. Hogan et al. address the limitations in analyzing the impact of support groups, because support groups are voluntary and those who attend support groups are generally reported to have a higher socioeconomic status, higher stress, more access to social support networks, are more likely to take advantage of professional assistance, and utilize coping strategies more often than individuals who do not attend support groups. Access to groups is limited for individuals who have a lower SES and for people with little or no social support because many people with PD are not able to drive due to their diagnosis and transportation can be difficult to access based on several different factors.

Support groups and self-help groups can help people living with PD by preventing isolation and increasing social competence and adjustment to the disease. (Charlton & Barrow, 2002). Support groups provide a space for patients to address needs that they may not be able to discuss at doctor's visits and can help patient's cope with and learn to accept the disease (Dorsey, Voss, Shprecher, et al., 2010). In the US survey on PD conducted from 2006 and 2007, 61% of respondents had attended a support group at least once and 79% of those had attended a group in the last year. Patients who were seeing a PD specialist were more likely to attend a support group than patients who were seeing a neurologist without a PD specialty. The survey found that 49% of those surveyed reported overall high levels of satisfaction with their support group. Individuals who attended support groups reported satisfaction with the information they received from other individuals living with PD and group leaders and reported a sense of community with the group. 43% of respondents reported satisfaction with the emotional support they felt they received from the group. There were a few participants who reported a concern that the group didn't meet their specific PD needs, for example, they felt like information shared by others made them concerned about how difficult the future could be with the progression of the disease. Others reported concern about the lack of training and expertise from the leaders and other attendees in the group and accessibility and difficulty in getting to the group. The value of support groups could be increased by being more accessible and bringing more awareness about when and where they are, providing content that is more accurate and led by individuals with expertise, and making groups more homogenous.

Lieberman, Wizlenberg, Golant, & Minno (2005), conducted a study on the impact of homogenous PD groups vs. heterogeneous PD groups to see if there was a difference in reported outcomes from the group. The concept for this study came from the viewpoint that people who share similarities are more likely to build closer bonds more quickly and to have more cohesion within the group. The study had sixty-six participants who completed a questionnaire on the study's website and the were broken into 6 different groups. Three of the groups were heterogeneous with a range in age and time since their diagnosis and three of the group were homogenous, with two groups for young onset PD and one group for newly diagnosed within the last 2 years. The group met weekly online for 90-minute sessions and were able to facilitate chats on a discussion forum through the week. Unique to this study is that the group facilitators were trained mental health professionals, who also received extra training specific to PD in order to learn how to navigate and facilitate the discussions of the group in a more comprehensive fashion. Only 32 participants were able to fully complete the full length of the study intervention. Members of the homogenous group reported more commitment to their group than those in the heterogeneous group by a significant amount. Members of the homogenous groups saw greater overall changes in symptoms of PD and depression. Members of the homogenous group saw an increase in depression symptoms. All groups saw an improvement in quality of life during their attendance in the group. There are mixed reviews from the group participants about the limitations or benefits of an online group vs a face to face group. Some reported they feel more comfortable discussing certain topics that they might feel embarrassed about in a face to face group. Others reported that online support groups can be difficult because you can't see the expressions of others faces and aren't able to see their physical bodies to offer support in different ways. Online support groups are beyond the scope of this paper but provide an interesting consideration for the opportunity of providing support and movement in an online format and what they might look like.

The Parkinson's Foundation provides a Parkinson's support group manual on their website that with information about how to start and run a support group in a step by step fashion and provides resources for people to contact for more information about PD and about how to run a successful group. The manual outlines what a group is not and what a group is. The list of what a group is not, includes a place where people come to feel more burdened by the disease or to feel more blessed or lucky based on the shared experiences or hardships of others, it is not a therapy group or a replacement for medical treatment or individual counseling sessions. The manual states that a PD support group is a self-help group where individuals can share their challenges, a place to be educated about the disease, share information and offer support, and a place where caregivers and family members can get support. (Parkinson's Foundation, Support Group Guide (n.d.) Retrieved from

https://www.parkinson.org/sites/default/files/attachments/SupportGroupGuide_121917_spreads. pdf). One of the biggest limitations for PD support groups reported by attendees is the lack of training for group facilitators. Anybody who is interested in starting a group can find the support group manual on the PD website and start a group. This can lead to frustration within the group of not having someone who has expertise in managing group discussions and can lead to groups that get off track or derailed easily.

Impact of Combined Support and Movement Group

Michels, Dubaz, Hornthal, and Bega (2018), conducted a study on the benefit of using dance therapy as an intervention for people living with PD. Dance therapy combines traditional therapy or "talk therapy" with a body-centered focus in striving to meet the physical, social, emotional, and cognitive needs of the individual or group (ADTA, 2019). The writers set out to see how well dance therapy would be received by the PD community and the impact of a dance therapy intervention on the motor and non-motor symptoms of PD. The study included 13 participants who attended 60-minute weekly sessions for 10 weeks. Each session was facilitated by a board-certified dance therapist and licensed clinical counselors. Each session focused on emphasizing an understanding about how movement impacts mood and mental health, gait, balance, and coordination, and the expression of feelings, emotions, and thoughts through movement. Following the movement, a support group format followed the included discussions about how movement impacts mood, how to use movement from the class in daily life

experiences, and an exploration of feelings. There was a control group that did not practice physical exercise and discussed the importance and impact of movement and different kinds of movement they could incorporate in their lives. The study was a pilot study to see if the group would be safe, feasible, and enjoyable for patients with PD and the study met all three criteria. After the study was completed, individuals from the control group requested to participate in a dance therapy group and the instructor was able to comply by provided another 10-week group. The study suggests that dance therapy can have a positive impact on motor and non-motor symptoms for PD. Dance therapy can improve rigidity, gate, and balance. The study of dance on people living with PD has demonstrated an improvement in cognition, decreased depression and apathy, and improved quality of life. The difference between dance classes and dance therapy is the approach to the whole body and bringing awareness to the participants of the connection between their minds and their movements. Dance therapy allows participants to express their feelings and emotions about the disease through movement and allows them to take notice of how their emotions impact how their bodies move. The writers proport that the potential benefits of dance therapy may provide more accessibility for patients with PD to therapists by combing dance and therapy into one setting because it provides the support of the group with the expertise of a licensed counselor in the room who can also facilitate movement in a therapeutic and healing way.

Emma Barton (2011) conducted a study on movement and mindfulness at a county based psychosocial rehabilitation facility for individuals with various mental illnesses. The facility offers outpatient long term care, extended care groups, and rehabilitative services. Participants voluntarily attended a 20-week movement and mindfulness group. The intervention was a combination of Dance/movement, yoga, and mindfulness and was used as a piolet study to see if the benefits of the group would necessitate a regular movement group as part of treatment at this mental health facility. The study has some limitations that included having a small sample size of only 8 participants, there was no control group, and the outcomes were gathered by the leader of the group creating a bias. The data from the group involved surveys and interviews from attendees of the group and were collected several times through the course of the group in order to compare reports and progress over time. The goal of the group was to help members learn to relate to others, learn to develop insight into their feelings, learn self-expression through movement, development of coping skills that can be used in daily life, and improvement of interpersonal communication and relationship skills. Participants identified improved ability to relax, greater ability to manage stress, decreased anxiety, better understanding and awareness of self, others, and thoughts and feelings as coping skills developed during the group (Barton, p. 168-169). Participants also reported improved relationships and social connections and reported that mirroring with other participants was a way to describe their internal shared struggles nonverbally which helped create an increased feeling of trust in the group. Staff members also reported increased social interactions and increase participation in other activities from those who attended the movement and mindfulness group.

This study was included in this literature review for the purpose of demonstrating the value of movement as compared to a regular "talk-therapy" setting. Participants of this group were members of the community rehabilitation program and attended several groups each week, but based on this study, it is demonstrated that through the sharing of movement, these individuals were able to develop lasting coping skills and create social connections, when they otherwise were reported by staff as having struggled with those skills before the group (Barton, 2011).

Data gleaned from a retrospective internship experience in working with PD

The writer's experience in facilitating a movement and support group for residents living with PD, supports the information gathered from this literature review about the value of dance classes and support groups as treatment for people living with PD. As a group facilitator, it lends support to the value of talking together as a group about the frustrations of living each day with PD, the struggle that comes with losing functionality and the ability to do things they way a person is used to, and how talking provided a space for relief and support. The group came together by sharing how they learned to overcome struggles and obtacles they encountered with PD. Moving together provided a space for inidividuals to shed their fear about their tremors and other movement limitations they were experiencing that were keeping them from leaving their room and attending social gatherings. Individuals who attended the group were able to open up in the group and this opening up seemed to filter into their time outside of the group as they began to leave their rooms, attend more social functions, and to interact with other people. This experience is consonant with the experience of participants in the Houston and McGill (2013) study who said that moving and dancing together is a better way to get to know each other than simply talking. The writer observed a similar phenomenon in the coming together of people through words and movement.

At a skilled nursing facility in Quincy, Massachusetts, a previous pilot support and movement group was facilitated by the writer as a dance/movement therapy intern. The nursing facility housed residents with a diagnosis of Dementia at varying stages. Before beginning the group, PD was researched and the PD website was utilized to gain insight into the disease and to understand the resources available to people living with PD. The PD support guide book was used for help and ideas of how to facilitate a group. At that time, the writer worked with the activities director and pulled a list of the residents at the facility who had a diagnosis of PD and from the list of residents with a diagnosis of PD, the residents were selected based on their ability to engage in verbal conversation. The total number of participants was 5 and the group ran for 10 weeks. Attendance varied from week to week due to illness, appointments, and timing of nursing availability for transport to the group. Other obstacles to getting the group started and encouraging attendance included fear and embarrassment of symptoms. One resident experienced hesitation in attending because he reported he was embarrassed by his tremors and didn't want to deal with the stress of his tremors increasing because of his embarrassment and stress caused by being in a new environment. Initially it was difficult to get everyone to the group because of the time of the group, nursing couldn't have everyone ready for the day, so the group was moved to a later time in the day to avoid that obstacle. Once the group moved to afternoons, the group began to be more cohesive because more people were ready and able to come and by the last 4 weeks, the full group attended each week.

The group was held weekly for 45 minutes. The first week of the group focused on the group and what they wanted to learn about PD, issues they wanted to discuss, and what the group was going to look like each week. The group was diverse in mobility and cognitive impairment, including having dementia, and these were all important factors to take into account in planning the group discussion and in finding a way to provide support and movement for the group.

The weekly group started with a 20-25-minute discussion about a topic suggested by the group during the previous week. Topics over the 10 weeks included the impact of movement on motor and non-motor symptoms of PD, tools and tricks to use for improving memory, and discussion about the stress and frustration of different symptoms and how to cope with stress, to

name a few. The group would start by reading facts and information from the Parkinson's website or research found on the specific topic and then the conversation would open to the group for discussion. Discussion came slowly at first, as the group got to know each other and build trust. By the third week, group members asked to discuss how to remember things and issues with memory, several members of the group shared their tips to improve memory and tricks for remembering, which helped to bring a new element of group discussion and trust within the group.

After the discussion portion of the group, the last 20-25 minutes were spent moving together. The movement was done while sitting in chairs and wheelchairs for safety reasons, since there were no group support leaders to facilitate safe movement out of their chairs. Movement began with a warm-up that was the same every week and began with a breathing exercise. Members of the group were encouraged and reminded to move in way that felt comfortable and safe for them that day. After the warm-up, movement included imagery that would illicit a discussion or conversation as we moved together, like marching in a parade and waving at the attendees or reaching for an apple or a cookie jar. The movement and imagery varied each week and would be determined by the mood of the group based on the support discussion that happened before we moved together. The conclusion of the group included each member of the group doing a movement that the group would repeat back to them together and then we would end with the same breathing exercise we started with.

There was no formal data collection before or after the group to determine the benefits or outcome of the group, which is a limitation. The anecdotal data is collected from discussions with attendees about their experience. Individuals in the group reported that the group gave them something to look forward to each week and they were sad it wasn't going to be a permanent thing, because of staff limitation to continue the group once the internship was completed. One attendee reported feeling better knowing other people had PD and that they weren't alone (Personal Communication, April 2018). Before the group, 4 of the 5 residents with PD stayed in their rooms and seldom attended activities and chose to eat their meals in their rooms. The activities director reported that she noted a difference in residents spending less time alone and, in their rooms, and engaging in more social activities throughout the building. She also noted that doing movement allowed them to get out of their comfort zone and try something new (Personal communication, May 2018). To provide an example of the group bringing people together and getting them out of their rooms, two residents stories will be shared. One resident with a diagnosis of PD had somehow been left off the original list of participants, but his neighbor across the hall, who was coming to the group and knew this man had a PD diagnosis, told him about it and invited him to come. These two came to group together every week after that.

Over the course of the 10 weeks, the group discussions became more conversational, group members interacted with each other outside of the group, the group members became more comfortable within the group setting and moved more freely together. One resident began taking daily walks through the halls and talking to more people after he began attending the PD group. Before the PD group he had stayed in his room all day and almost never interacted with other residents. There is no verifiable data that the group is what encouraged him to spend more time out of his room and to interact with others, but the correlation is there and worth investigating.

These experiences were recorded while leading the group in a personal journal about the group in the 4th week of the group:

"The Parkinson's group is coming together, the group seems to be building relationships and connections with each other and they are opening up more about their challenges and struggles and exchanging ideas with each other about how they manage certain symptoms or tricks they use for remembering things" (Personal Communication, April 2018).

The writer was moved by how willing the group was, once there was a consistent flow of attendance and timing, to share with each other and to support each other. The author struggled to know the right time to begin to move together, and the first couple of mettings took place without moving together because of the timing and people not being able to attend. It was interesting to try to figure out the best way and time to begin moving together, as reflected in the leader's personal journal:

"Figuring out how to transition from support to movement has been tricky, but it feels like we are at a point that makes sense and it gives the members of the group the opportunity to move together without feeling embarrassed about tremors and other obstacles in movement from PD. When we move together, I feel like walls begin to come down and there is more cohesion in the group" (Personal Communication, April 2018).

The progress of the group began to feel more advanced once we began to move together. The first week or two of moving together included hesitation and embarrassment in not being able to do all of the things exactly as asked due to physical limitation, but everyone was encouraged to move as they could and to not feel embarrassed and to do the best they could in whatever way they could. As we continued from week to week to move together, people appeared to not be as worried about their visible symptoms or about what other members of the group might be thinking, but we were able to talk more casually and freely when we moved and laughed about

the imagery for the movement. A clear bias from these observations is that moving together brought the group closer and allowed for more cohesion in the discussion and the movement.

Discussion

Further research is needed on whether combining movement and support as part of treatment will provide an added benefit for people living with PD. As demonstrated in this literature review and from the writer's personal experience as a movement and support group facilitator, individuals who attended dance classes reported improved quality of life, improved social interactions and connections, improved ability to complete daily activities, and improved mood. Dance classes provide a space for individuals living with PD to find unique ways of meeting people who share similar experiences, and a space to learn skills and techniques that improve cognition, gait, and improved posture (McRae et al., 2018). Support groups provide a space for people with PD to share their fears, to learn more about the disease and available treatments, and to experience a decreased sense of isolation. The writer's bias, based on her experience facilitating a movement and support group and encouraged by this literature review, is that combing movement and support provides an added measure of group cohesion, an increased feeling of support from the group with a decreased feeling of isolation, and increased quality of life.

Dance classes for PD are led by trained dancers who go through training to become certified as teachers and the classes have goals that include improving gait, balance, and cognition. There is training available for support group leaders through the PD organization if leaders have interest in and ability to attend the annual training. This writer would be interested to know the benefit and outcome of support groups if instructors were required to do a training before they begin facilitating a group. This is especially relevant in the feedback from support

22

group attendees that they feel they would benefit more if there were experts or trained professionals leading the groups (Dorsey et al., 2010).

This writer would like to continue expanding on the existing research reviewed here and implement the integration of movement in already established support groups within local communities. Data collection could be utilized to assess how attendees feel about the support group as it is, an assessment of how attendees feel during the process of implementing movement, and how attendees feel after an extended period of combined support and movement. Interviews could be gathered from attendees on their experience and this information could be used to validate or invalidate the value of combining support and movement as an additional resource of treatment for people living with PD.

Research for dance classes and support groups confirm decreased isolation and increased socialization in people living with PD. Based on the evidence from this literature review and personal experience in facilitating a combined group, the outcome of combing movement and support has the potential to be decreased isolation, improved mood, improved cognition, gait, and balance, and most importantly improved quality of life. A combined movement and support group could improve motor and non-motor symptoms of PD and could provide a more cohesive mental, physical, and emotional support than attending dance classes and support groups separately.

Artistic Expression

Whilst engaged in undertaking this research, articistic representation of the heart took shape in phases. I started with the anatomically correct heart because this is a topic that is close to my heart. I loved working with the elderly with dementia and I loved being able to bring a group to my residents living with PD. I loved watching the group find support with and for each other and providing something the group participants looked forward to each week. My heart has been changed by those people and the experience I had in being able to facilitate a support and movement group. I expanded on the drawing of heart by addin the warm colors surrounding it because that is how I felt from the support of the people helping my bring the group to life and how I felt after each group and learning from the group members. There was a warm, love, and compassion that formed in the group and in my heart. I hope to continue to bring that light, support, and love to each group I lead and especially in the work I hope to do in the future with PD support and movement groups.





This final picture was a process I explored during a weekend thesis class. I had planned to do a community engagement thesis, but with limited ability to attend local groups, the decision was made that I would do a literature review. I felt a sense of relief and a sense of

PARKINSON'S DISEASE, MOVEMENT AND SUPPORT

sadness. This glitter started as a straight lines with a clear picture, like my thesis did for me. I began to use the glitter tips to squiggle the lines and make the path less clear and more flexible to match my new plan going forward to do a literature review. I added the shapes to demonstrate obstacles and supports I might encouter along the way of doing my thesis and in continuing this work in the future.



This literature review has provided this writer the opportunity to begin building a foundation for future research. A thorough reflection of the literature review, personal experience, and artistic exploration has solidified this writers committ to pursing further research on combined movement and support.

References

American Dance Therapy Association (n.d.) Retrieved from https://adta.org/faqs/.

- Ashburn, A. et al. (2015). Dancing with Parkinson's disease: a qualitative exploration of the views and experience of participants in a feasibility study. *Physiotherapy*, *101*, e90 e91. <u>https://doi.org/10.1016/j.physio.2015.03.222</u>.
- A U.S. survey of patients with Parkinson's Disease: satisfaction with medical care and support groups. *Movement Disorders*. 25(13), 2128-2135.
- Barton, E. J. (2011). Movement and Mindfulness: A Formative Evaluation of a Dance/Movement and Yoga Therapy Program with Participants Experiencing Severe Mental Illness. *American Journal of Dance Therapy*, (2), 157. Retrieved from http://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true& db=edsgao&AN=edsgcl.273197590&site=eds-live&scope=site.
- Charlton, G. S., & Barrow, C. J. (2002). Coping and self-help group membership in Parkinson's disease: an exploratory qualitative study. *Health & Social Care In The Community*, *10*(6), 472–478. Retrieved from

http://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true& db=cmedm&AN=12485134&site=eds-live&scope=site.

- Dale, A.J., Hyatt, J. & Hollerman, J. (2007). The neuroscience of dance and the dance of neuroscience: defining a path of inquiry. *Journal of Aesthetic Education*, 41(3), 89. https://doi-org.ezproxyles.flo.org/10.1353/jae.2007.0024.
- Delisle, V. C., Gumuchian, S. T., Rice, D. B., Levis, A. W., Kloda, L. A., Körner, A., & Thombs, B. D. (2017). Perceived benefits and factors that influence the ability to

establish and maintain patient support groups in rare diseases: A scoping review. *The Patient*, *10*(3), 283-293. doi:http://dx.doi.org.ezproxyles.flo.org/10.1007/s40271-016-0213-9.

- Earhart, G. M. (2009). Dance as therapy for individuals with Parkinson disease. *European Journal Of Physical And Rehabilitation Medicine*, 45(2), 231–238. Retrieved from http://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true& db=cmedm&AN=19532110&site=eds-live&scope=site.
- Hashimoto, H., Takabatake, S., Miyaguchi, H., Nakanishi, H., & Naitou, Y. (2015). Effects of dance on motor functions, cognitive functions, and mental symptoms of Parkinson's disease: A quasi-randomized pilot trial. *Complementary Therapies in Medicine*, 23, 210–219. <u>https://doi-org.ezproxyles.flo.org/10.1016/j.ctim.2015.01.010.</u>
- Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions. do they work? *Clinical Psychology Review*, 22, 381–440. https://doi.org/10.1016/S0272-7358(01)00102-7.
- Houston, S., & McGill, A. (2013). A mixed-methods study into ballet for people living with Parkinson's. *ARTS & HEALTH*, 5(2), 103–119. <u>https://doi-org.ezproxyles.flo.org/10.1080/17533015.2012.745580</u>.
- Lieberman, M. A., Wizlenberg, A., Golant, M., & Di Minno, M. (2005). The impact of group composition on internet support groups: homogeneous versus heterogeneous parkinson's groups. *Group Dynamics: Theory, Research, and Practice*, 9(4), 239–250. https://doi.org/10.1037/1089-2699.9.4.239.

- McRae, C., Leventhal, D., Westheimer, O., Mastin, T., Utley, J., & Russell, D. (2018). Longterm effects of Dance for PD® on self-efficacy among persons with Parkinson's disease, *Arts & Health: International Journal for Research, Policy & Practice*, 10(1), 85–96. https://doi-org.ezproxyles.flo.org/10.1080/17533015.2017.1326390.
- Michels, K., Dubaz, O., Hornthal, E., & Bega, D. (2018). "Dance Therapy" as a psychotherapeutic movement intervention in Parkinson's disease. *Complementary Therapies in Medicine*. https://doi-org.ezproxyles.flo.org/10.1016/j.ctim.2018.07.005.
- Parkinson's Foundation, (n.d), Retrieved from <u>https://parkinson.org/understanding-</u> parkinsons/what-is-parkinsons.
- Rajesh Pahwa (2009). Parkinson's disease. Oxford University Press, USA 2009. Retrieved from <u>http://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true&</u> <u>db=cat05473a&AN=les.2316898&site=eds-live&scope=site</u>.
- Sharp, K., & Hewitt, J. (2014). Review: Dance as an intervention for people with Parkinson's disease: A systematic review and meta-analysis. *Neuroscience and Biobehavioral Reviews*, 47, 445–456. <u>https://doi-</u>

org.ezproxyles.flo.org/10.1016/j.neubiorev.2014.09.009.

Weiner, W. J., Shulman, L. M., & Lang, A. E. (2007). Parkinson's disease : a complete guide for patients and families. Baltimore : Johns Hopkins University Press, 2007. Retrieved from http://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true& db=cat05473a&AN=les.1044284&site=eds-live&scope=site.

THESIS APPROVAL FORM

Lesley University Graduate School of Arts & Social Sciences Expressive Therapies Division Master of Arts in Clinical Mental Health Counseling: Dance/Movement Therapy, MA

Student's Name: <u>Sara Schmidt</u>

Type of Project: Thesis

Title: Movement and Support as Treatment for Parkinson's Disease: A Literature Review

Date of Graduation: May 18, 2019

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: Vivien Marcow Speiser_