

THE EFFECTS OF INTERPERSONAL VARIABLES AND DANCE ON THE WELL-BEING
OF INFORMAL CAREGIVERS

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ABSTRACT

The purpose of this research was to explore how interpersonal variables and dance may benefit caregivers. In Study 1, 20 couples coping with Parkinson's disease (PD) were surveyed about their attitudes toward their partners, in general, and also within a Dancing with Parkinson's (DwP) class. Appreciation for one's partner was associated with greater relationship satisfaction, and when care partners reported more self-expansion, they were more satisfied in their relationship, and reported less caregiver burden. When couples attended DwP together, both care partners and PwPD reported feeling more positive emotions towards their partner. In Study 2, a pilot dance movement therapy (DMT) group for parents who have a child with Autism Spectrum Disorder was assessed. Five parents reported that DMT was self-expanding, burden relieving and elicited social support, mindfulness, and fun. Dance interventions for caregivers should continue to be investigated, with larger and more diverse samples.

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INTRODUCTION

Neurological conditions such as Autism Spectrum Disorder (ASD) and Parkinson's disease (PD) have poignant personal and relational impacts on the lives of those affected, as well as on caregiving spouses and parents. Statistics Canada estimates that more than 8 million Canadians provide informal care to a family member or friend (StatsCan, 2020) and that 160,000 spouses are full time care partners due to their partner's fragility, cancer, dementia or other neurological conditions (e.g., Parkinson's). Furthermore, 1.6 million caregivers in Canada take time off work to provide care, and one-in-ten caregivers spend more than 30 hours per week providing care to their loved one (CARP, 2015). These statistics are important to consider because caregiving for an individual with a neurological disorder is typically associated with unique burden, and negative emotional consequences (Pinquart & Sörensen, 2007) for spousal care partners (Martinez et al., 2018; Miller et al., 1996), and parental caregivers (Khanna et al., 2011; Stuart & McGrew, 2009).

Past research has considered the relationships between PD symptoms and care partner burden, and quality of life (Caap-Ahlgren & Dehlin, 2002; Mavandadi et al., 2014), and found that when a person with PD has more depressive symptoms and impairment, their care partner reported more depression and emotional distress (Aarsland et al., 1999; Martinez et al., 2018). However, little research has considered the dyadic adjustment of these couples, or what personality factors and/or activities may promote relationship and satisfaction (Ricciardi et al., 2015). Similarly, while it has been established empirically that caring for a child with ASD is associated with parental stress and burden (Higgins et al., 2005), investigating which activities address these parent's needs to help them cope more effectively has not been emphasized in the literature (Phetrasuwan & Miles, 2009).

The specific challenges of PD and ASD as well as how these symptoms affect well-being for couples coping with PD, and parents of a child with ASD will now be discussed. The protective factors and interventions that have been considered so far for these informal caregivers will also be considered.

Parkinson's disease

In Canada, 1 in 500 people have been diagnosed with Parkinson's disease, which is over 100,000 Canadians (Wong, Suzy, Gilmour, Heather, Ramage-Morin, 2014). PD is a multi-dimensional neurodegenerative disorder that currently has no cure. PD develops from loss of cells in the brain that produce dopamine. Medication treatments such as L-DOPA, and other forms of therapy, may be prescribed to help reduce symptoms, but these cannot stop the disease progression. On a physical level, people with PD (PwPD) are affected by motor symptoms such as postural instability (i.e. difficulty maintaining steady posture, balance), rigidity, tremors and impaired functional mobility (Hoehn & Yahr, 1998). PD also affects individuals on psychological and relational levels.

Psychological and Relational Consequences of PD for People with PD

People with PD experience emotional and cognitive impairments such as depression, anxiety, difficulties with facial encoding, empathetic response and communication, and impaired sexual functioning (Dujardin et al., 2004; Heiberger et al., 2011; Miller et al., 1996; Narme et al., 2013; Wielinski et al., 2010). In general, PwPD seem to experience higher rates of depression, compared to healthy controls and people with other chronic conditions (Nilsson et al., 2002). Depressive symptoms, disease severity, cognitive impairment and insomnia have also been associated with lower degrees of quality of life, for PwPD (Schrag, 2006). Relationally, PwPD may experience poorer relationship satisfaction compared to their caregiving spouses (Ricciardi

et al., 2015), which may be due to the fact that their partners lack the skills to function in the double role as a caregiver and romantic partner. Furthermore, people with PD are significantly worse at recognizing emotions than their caregivers, and this deficit in people with PD is associated with increased care partner burden and depression (Martinez et al., 2018).

Psychological and Relational Consequences of PD for Care Partners

Care partners of PwPD report more depressive symptoms and poorer quality of life compared to healthy, non-caregiving individuals (Miller et al., 1996). Importantly, care partner depression and emotional distress has been found to be positively associated with the depression and degree of empathy impairment in their spouse with PD (Aarsland et al., 1999; Martinez et al., 2018). Furthermore, when care partners report being more depressed themselves, and are less satisfied with their life and relationship, they also report more caregiving burden, among spouses caring for someone with PD (Schrag et al., 2006) or Dementia (Simonelli et al., 2008)

These statistics are especially pertinent to consider because prevalence rates of PD are on the rise, with an expected 65% increase from 2016 to 2031 (Government of Canada, 2014) and over one million spouses in Canada are full time caregivers for their partner's health (StatsCan, 2020), with 56% of PD patients reporting that their spouse is their fulltime caregiver (Wong, Suzy, Gilmour, Heather, Ramage-Morin, 2014). Therefore, given that PD is on the rise, PwPD rely on their spouse for support, and caregiving can have negative impacts on caregiver health, it is important to investigate how couples can better cope with PD.

Associations Between PD and Both Partner's Well-being

While very little research has considered how relationship satisfaction differs between couples dealing with PD and healthy age-matched controls, Braun and her colleagues (2009) considered what relational changes occur in couples coping with Dementia, another

neurodegenerative condition with a similar progressive trajectory as PD (M. Braun et al., 2009). By reviewing five dyadic research studies (e.g. couples interviews) they found that couples dealing with dementia had more disagreements about sex and intimacy compared to healthy couples. Furthermore, wives caring for a husband with dementia experienced less reciprocal support with their husbands, compared to non-caregiving wives, and this was associated with less relationship satisfaction (Gallagher-Thompson et al., 2001).

Protective Factors for Couples Coping with PD

Given that the caregiving relationship is by definition made up of two individuals, and the potential for PwPD and their care partners to be negatively affected by their disease, determining what factors can protect well-being for both members these couples is essential. So far, the available literature suggests that appreciation, communal strength, and self-expanding activities that promote personal and relational growth may be beneficial.

Appreciation. In community samples of couples, appreciating one's partner, as well as feeling appreciated by one's partner are associated with successful maintenance of ongoing romantic bonds, and greater relationship satisfaction (Gordon, Impett, Kogan, Oveis, & Keltner, 2012). Furthermore, when people experience feeling grateful or appreciative for their relationship, they report engaging in more relationship maintenance behaviours (Kubacka et al., 2011). On the flip side, when partners do not feel loved and/or appreciated by their partners, this is a top reason for divorce (Gigy & Kelly, 1993). Appreciation has been considered in the literature for spousal caregivers of a partner who has cancer, and being more appreciative for one's partner and the opportunities their diagnosis has provided (e.g. "having cared for my spouse through his/her cancer led me to meet people who have become some of my best friends") predicted care partner life satisfaction, and better adjustment, with fewer depressive

symptoms (Y. Kim et al., 2007). These findings have also been echoed in a pilot study with couples coping with PD (Mavandadi et al., 2014). While this work is encouraging, there are still many gaps in researchers' understanding of how appreciation may affect personal and relational well-being for care partners and PwPD.

Communal Strength. Since caregivers spend a considerable amount of time providing tangible care to their loved one, an important factor to consider is partner-specific *communal strength* (CS): the motivation to care for a romantic partner, friend, or child's specific needs (Le et al., 2018; Mills et al., 2004). In community samples, people higher in CS report greater relationship satisfaction, related to the intrinsic joy they may experience by caring for their partner's needs. Recipients of the care also experience greater relationship satisfaction when their partner is higher in communal strength (Le et al., 2018). This is relevant for couples coping with PD, because how one is motivated to meet the needs of others becomes more salient when one partner is diagnosed with a progressive disorder, such as PD, that elicits more needs to be met, and also restricts the patient's ability to meet their partner's needs. It is unknown if communal strength may help to buffer against care partner burden. Work in other clinical samples (e.g. cancer) shows that while communal strength is associated with positive outcomes, *unmitigated communion* (focusing on other's needs to the exclusion of one's own needs) (Fritz & Helgeson, 1998) is associated with negative outcomes such as illness, psychological distress, and poorer adjustment to living with a disease (Helgeson, 2003). This aspect of communal motivation is particularly relevant among couples coping with PD because it is possible that among couples coping with a neurodegenerative disorder that care partners become so focused on their spouse that they neglect their own needs. Unmitigated communion may be associated with distress and ill-being because individuals with unmitigated-communion are providing

support, but not receiving it (Helgeson, 2003). Therefore, it is important for both partners to remain communal and attentive to one another's needs, especially when physical and cognitive needs are amplified by a clinical condition. While associations between communal strength and well-being have not yet been validated empirically among couples coping with PD, we would expect these findings to hold up. Furthermore, if interventions for couples coping with PD could provide an opportunity for partners to be communal, and care for each other's needs this may also be relevant as we consider what factors may buffer the negative effects of living with a progressive condition.

Perceived Partner Responsiveness. People who are highly communally motivated are typically very responsive to their loved ones needs. Consequently, the recipient of care typically experiences greater personal well-being (e.g. life satisfaction) and relational well-being (e.g. relationship satisfaction) when they perceive that their partner is responsive to their needs (Le et al., 2018; Lemay et al., 2007), and may also be inspired to be more responsive to their partner in return. Perceived partner responsiveness is a fundamental determinant of relationship satisfaction, and while it has not been considered in couples coping with PD, we expect that when either a care partner or PwPD perceives that their partner is responsive to their needs, that this would bolster their relationship satisfaction.

Self-Expansion. In community samples of couples, relational *self-expansion*: deriving a sense of novelty and expanding one's sense of self and perspective of the world from being with a romantic partner (E. N. Aron & Aron, 1996) is associated with greater relationship satisfaction in couples. What couples consider to be self-expanding varies based on the couple, but could range from dancing together, to going on a road trip. Aron and Aron (1986) posited that relationships will be more rewarding, committed and satisfying if they present opportunities for

the members to satisfy their desire to self-expand. In romantic couples, higher degrees of perceived self-expansion with one's partner have been related to greater relationship satisfaction and sexual desire for both oneself, and their partner, and that these effects sustain over time (Muisse et al., 2019). While no research projects on self-expansion have considered couples coping with PD, a construct that similarly focuses on positive growth of one's sense of self: *benefit finding*: experiencing personal growth or positive change after facing a challenge (Mavandadi et al., 2014) has been suggested as a protective factor for both care partners, and their partners with PD. PwPD's marital quality has been positively associated with their own benefit finding, and their spouse's benefit finding. Care partner marital quality was also associated with their spouse's benefit finding (Mavandadi et al., 2014).

A proposed mediator for self-expanding activities and relationship quality in community samples is positive affect, such that if the self-expanding activity is experienced as active, engaging, and involved with one's partner it may be particularly important for boosting relationship satisfaction (A. Aron et al., 2013; Strong & Aron, 2006). Along these same lines, it is proposed that self-expansion may buffer some of the challenges of coping with a clinical issue (e.g. sexual distress) (Raposo et al., 2020) because self-expanding activities provide couples with a source of positive emotional *capital*: a compilation of positive exchanges between partners that make them feel connected and important (Walsh et al., 2017). Therefore, given the positive outcomes associated with personal growth for care partners and PwPD, and the potential for self-expansion to buffer negative relationship experiences, it is important to investigate if self-expanding activities that elicit positive emotions could help to boost personal and relational well-being for couples coping with PD, and reduce caregiver burden.

Interpersonal variables such as self-expansion and communal strength are also important to consider for parental caregivers, given the potential for them to buffer against negative outcomes. The consequences of ASD for parental caregivers, and what factors and interventions that may be effective for them will now be considered.

Autism Spectrum Disorder

1 in 66 children in Canada live with Autism Spectrum Disorder (ASD), with boys being four times more frequently diagnosed than girls (*Surveillance of Autism Spectrum Disorder (ASD) - Canada.Ca*, 2018). ASD affects many areas of development, and the extent of the effects range from nearly normal behavior to severe symptoms. The core developmental areas affected include: impairments in processing social and emotional information, verbal and nonverbal communication, and ritualistic, repetitive, sometimes aggressive behavioral patterns (Lake et al., 2014).

Psychological and Social Consequences of ASD for Parental Caregivers

Some especially stressful factors that arise from parenting a child with ASD include the permanency of the life-long condition, personal and family burden, financial challenges, social isolation, the lack of acceptance of autistic behaviours by family members and society at large, and the low levels of accessible support from health care providers and social service centers (Higgins et al., 2005; Sharpley et al., 1997). Parenting a child with ASD also adds to the ordinary necessary tasks of the parent, from the need to be more vigilant to manage aggressive behaviours, being more hands-on due to the child's potential lack of self-care skills, and the ongoing need to advocate for the child in the education system (Phetrasuwan & Miles, 2009). Additionally, parental caregivers of a child with ASD are at risk for social isolation, due to the time and energy demands placed on them, which limit their ability to engage in social activities

(Higgins et al., 2005). Correspondingly, parents and families report more burden when their child's ASD symptoms are more severe (Khanna et al., 2011; Stuart & McGrew, 2009). While there is minimal research concerning buffering the negative effects of burden for parental caregivers of a child with ASD, it is essential to investigate interventions that can assist these parents, as rates of ASD are on the rise. It is estimated that in 1981, rates were 1:10,000 (Christensen et al., 2016) compared to now 1:66 children have been diagnosed with ASD. An available review does capture contributing factors, and psychological outcomes of ASD-related parental coping (Lai & Oei, 2014). The review revealed that parents utilized both problem-focused (e.g. treatments, reframing) and emotion-focused coping strategies (spirituality, respite, social support groups).

Protective Factors and Interventions for Parental Caregivers' Well-being

Social Support and Mindfulness. Social support appears to be an essential protective factor against mental distress for parental caregivers. Lai and Oei's (2014) review suggests that lower depression, anxiety and more positive moods was found to be associated with seeking social support, and cognitive reframing. The review also points out that mental health professionals need to be mindful to propose specific coping mechanisms that can equip parents to experience more positive outcomes (Lai & Oei, 2014). A recent review of interventions to target improvements in mental health for parents who have a child with ASD (Da Paz & Wallander, 2017) delineated what intervention modalities have been tested thus far, ranging from cognitive behavioural therapy (Feinberg et al., 2014), expressive writing (Campbell, 2003), to mindfulness and relaxation training (Ferraioli & Harris, 2013). This review covered the 13 available studies, with sample sizes ranging from 3 to 200 participants. Common outcome measures included satisfaction with life, personal growth, and family functioning. Mindfulness-

based modalities and relaxation trainings that focused on being present, and breathing techniques were found to have medium to large positive effects, reducing parental stress and depression (Da Paz & Wallander, 2017). While some of these interventions were group-based and others were individual sessions, Da Paz and Wallander concluded their review by emphasizing the need for future interventions to facilitate social support, as social support is a well-regarded protective factor for parental caregivers that can mediate parenting stress, decrease family burden, and promote parental happiness (Blake et al., 2019). While higher levels of general and specific contextual support have been found to be directly related to decreased parental, and family burden (Stuart & McGrew, 2009), what constitutes “social support” is a wide range of possibilities from befriending parents who also care for a child with ASD (Blake et al., 2019), to extent of marital/family adaptation (Dunn et al., 2001). Therefore, understanding what specific forms of social support are most beneficial is important if optimal interventions are to be put in place for parental caregivers.

Communal Strength. While most of the research on CS and well-being outcomes has considered romantic partners, it is important to consider how this association may also extend to parent-child relationships, if having a CS orientation is associated with greater personal and relational well-being. Research on communal strength in parents has found that communally motivated parents felt a greater degree of authenticity in their caregiving, which was then associated with greater emotional well-being, and a higher quality of relationship with their child (Le & Impett, 2015). These associations could not be contributed to care difficulty, child’s mood, or specific caregiving behaviours; however, this was a community sample and was not focused on caring for children with disorders such as ASD. Furthermore, communal parental goals of meeting child’s emotional needs such as desiring that one’s child know they are loved, and

important to them, as opposed to pursuit of self-oriented parent image goals (e.g. desiring to prevent the possibility that one's child will make them look bad) were found to be positively related to parent's emotional well-being, and responsiveness (Le & Impett, 2017). This work shows that among community samples, parent's degree of communal strength towards their child, as exhibited in their parenting goals and authenticity in caregiving had associations with greater well-being. This is particularly relevant for parents of a child with ASD, because their child may need more responsive care than a child without ASD, such as needing more hands-on assistance, and reinforcement (Phetrasuwan & Miles, 2009). Furthermore, given the high likelihood that parents caring for a child with ASD are at risk of distress and burden (Stuart & McGrew, 2009), determining if communal strength helps to protect well-being for these parents as well as investigating which interventions could help parents high in CS to be more able to respond to their child's needs is of utmost importance.

Self-Expansion. While self-expansion is proposed to be present in parent-child relationships (E. N. Aron & Aron, 1996), little to no research has actually considered what outcomes are associated with higher degrees of self-expansion in parents. However, it is quite plausible that parent-child relationships provide opportunities for parents to self-expand, as parenting comes with many new challenges for couples to face. In general, children's interests may expand a parent's knowledge about a particular activity or sport, and children may expand a parent's sense of who they are by causing them to be more patient, or other-focused. Furthermore, parents of a child with ASD may face even more opportunities to grow and self-expand by adapting to care for a child with unique needs, and who communicates in non-verbal forms (Lake et al., 2014). Correspondingly, Duncan, Coatsworth and Greenberg (2009) did find that improvements in relationship satisfaction among parents due to a mindfulness parenting

method were mediated by self-expansion, such that the parenting method improved relationship satisfaction because parents found it to expand their sense of who they were with their spouse (Duncan et al., 2009). While no other research to our knowledge has considered SE for parents of children with disorders such as ASD, if SE can enable greater relational and personal well-being it is important to consider what interventions could be self-expanding for these parents to take part in. Ideally then, an intervention for parental caregivers of a child with ASD would incorporate the components that appear to be effective so far in the literature such as expression, mindfulness, social support, and self-expansion.

Arts-based Interventions

In an attempt to help prevent declines in health for caregivers, and promote well-being within their context, arts-based interventions are worth considering because they aim to foster the factors that we know to be protective for personal and relational well-being. In 2019, the World Health Organization (WHO) released a synthesis report on the evidence of the role of *artistic activities*: complex or multimodal interventions that combine different components, such as sensory activation, imagination, emotional and cognitive stimulation, on psychological, physiological, social, and behavioral responses, which then may trigger beneficial health outcomes in the general population. For example, artistic activities may boost resilience, and quality of life, because they enable people to modify cognitions, and build social relationships with others (Papinczak et al., 2015). Dance and music specifically have been identified as protective against stress and depression (L. Martin et al., 2018). Notably, one of the subthemes of this report was how artistic interventions affect the well-being of formal and informal caregivers. Although research is minimal, art and music therapy groups seem to provide unique opportunities for informal caregivers and those receiving care to experience positive interactions,

respite, and improve communication and intimacy (Hammar et al., 2011; Hunt et al., 2018; B. Kim & Dvorak, 2018).

While creative interventions for informal caregivers utilizing art (Hunt et al., 2018) and music (Rio, 2009) have shown promising results, dance should also be considered.

The development of social support and empathy through group movement has been linked to lower stress and burn-out, and higher levels of resilience (Horwitz, 2018), which are essential factors to promote in caregivers. Dance involves the basal ganglia structures, and simultaneously activates neurological pathways similar to those of exercise, while supporting psychological states by boosting the concentration of serotonin (Heiberger et al., 2011). Based on these important impacts that dance can offer, two different dance-based interventions will be considered, with couples coping with PD, and parental caregivers of a child with ASD in mind.

Dancing with Parkinson's

Many interventions for people with PD have been put into place, with the goals of preserving functional capacity, and boosting quality of life. Recently, adapted dance for people with PD has been considered empirically more extensively. *Adapted dance* is recreational dance practice which has been modified to meet the special needs for a specific population of people (Les Grands Ballets, 2019). Weekly group Dancing with Parkinson's (DwP) classes, taught by trained professionals exist world-wide and encourage social interaction, learning partnered dance styles (e.g. waltz), and improvisation (DanceforPD, 2017). These classes are rooted in the class framework "Dance for PD" developed by the Mark Morris Dance Group in Brooklyn, NY and focus on developing technique and artistry (DanceforPD, 2017). Each class has time for learning choreography, improvisation and "mirroring" with a partner, which involves taking turns leading and following, coming up with improvised movement based on a specific theme or personal

story. The other partner then “mirrors” or echoes back this movement to the leader. This is a well-established technique, frequently used in Dance Movement Therapy and is hypothesized to increase connection and empathy (McGarry & Russo, 2011). This is particularly relevant because people with PD may suffer declines in empathy and other related cognitive functions.

Spousal care partners frequently participate DwP classes with their partner who has PD, as it is free for them to attend. When care partners attend dance with their partner, this provides an opportunity for them to be a part of their partners rehabilitation process, which is key for both partner’s well-being (Berger et al., 2019). While most of the present research on DwP has only focused on physical outcomes for PwPD, such as improved mobility (de Dreu et al., 2015) and shows that dance provides clinically meaningful improvements in motor skills for people with PD (dos Santos Delabary et al., 2018), some research has considered spousal care partners, and found increases in self-reported quality of life, and improved state of mind after class (Heiberger et al., 2011). However, it is unknown to what extent couples interacted with each other in these dance classes, which is essential if relational implications are to be drawn from such interventions. In a meta-analysis of the research considering benefits of dancing for couples coping with PD, there was a notable lack of information about caregiver participation in the findings of available research, and it is suggested that extent of care partner participation should be investigated further, as this may be associated with more optimal participant compliance (Aguilar et al., 2016). Moreover, Hackney and Earhart (2009) investigated the relationship between tango dance for PD, and health-related quality of life. Only the individuals with PD in the Tango intervention group (compared to Tai Chi, Waltz, Foxtrot, or no treatment) experienced increases in self-reported social support (Hackney & Earhart, 2009) yet, the authors state that this effect cannot be explained because all of the experimental groups involved participation with

loved ones. Furthermore, while they note that relationship-oriented goals with partners is of utmost importance for individuals with PD, partner effects of social support and relational outcomes were not investigated.

To date, there is very minimal dyadic research which explores how DwP classes are associated with couples' relationship satisfaction, or what specific aspects of the dance class are vital to relational outcomes. However, it is plausible to expect that dance provides opportunities for communal strength, responsiveness and self-expansion. A dance intervention such as DwP might be a way to demonstrate their communal motivation to their partner, if partners report being communally motivated in the dance class (e.g. feeling happy when doing something they know their partner enjoys in the dance class) this may be beneficial for both partner's relationship satisfaction. Secondly, if care partners have communal motivations for attending dance with their spouse (e.g. attend the dance class because they think their presence helps their spouse with PD), both partners might enjoy the activity to a greater extent.

Dance may also present opportunities for partners to be responsive to one another, in a way that is perceived by their partner, and thus helps to bolster relationship well-being. Dance enables partners to interactively respond to one another's needs, such as lending a hand for a partnered movement, or responding to a partner's movement story by mirroring their movements to indicate their empathetic understanding.

Furthermore, dance may elicit self-expansion in couples, as it may be viewed as an activity that is novel, and challenging (A. Aron et al., 2013); encouraging body movements other than ordinary motor activities, involving sight, sound, touch in a captivating multi-sensory experience (Hanna, 1995). It is likely that the majority of couples have never danced together,

and thus, this activity may be novel, and in turn, self-expanding especially if it elicits positive affect (A. Aron et al., 2013; Strong & Aron, 2006).

One study did consider the influence of different kinds of dance partners for PwPD in a ballroom dance class. Kunkel and colleagues (2018) conducted qualitative semi-structured interviews between PwPD who either danced with their spouse, a friend, or dance class volunteers, and thematically analyzed the data. They found that generally, PwPD who partnered with their spouse gained greater enjoyment and sense of achievement, compared to people with PD who danced with a volunteer whom they had less of a rapport with. It is suggested that relationship satisfaction and compatibility with one's partner are important factors to consider for dance enjoyment and benefits for PwPD. Specifically, couples who had danced together previously derived pleasure from dancing together again, and also couples enjoyed the novelty of dancing together, if this was a new experience for them (Kunkel et al., 2018). A common theme for spousal care partners who were interviewed in this study was enjoying the social interaction of dancing with their partner, the opportunity to see how other couples cope with PD, and a sense of satisfaction from seeing their partner with PD derive benefits from dancing. These thematic findings are a good starting point, and are aligned with previous work that suggests that dance has the potential to strengthen relational bonds, elicit boosts relational health (A. Behrends et al., 2016) and bring about "collective joy" (Ehrenreich, 2006). While a small body of research on DwP suggests possible benefits for care partners, these are all theoretical with no quantitative evidence. For example, a research project on the benefits of partnered dance for couples coping with PD suggests that partnered dancing may improve functional mobility of PwPD but also decrease caregiver burden, through mechanisms of empowerment and self-management (de Dreu et al., 2015). Furthermore, It is often suggested that relationship satisfaction in couples managing

PD may be benefited by dance due to the social nature of the class, but this has not yet been empirically validated (Westheimer, 2008). These proposed associations will be built upon specifically in the present work by considering the extent of couples interaction with one another in the dance class, as well as partners dance-specific communal strength, and perceived self-expansion in the dance classes.

Dance Movement Therapy for Parental Caregivers

In recent years, the research on the potential benefits of arts-based therapies for *children* with ASD has proliferated. For example, art therapy (Emery, 2004; N. Martin, 2009) drama therapy (Ramamoorthi & Nelson, 2011), and dance movement therapy (Koch et al., 2015; Koehne et al., 2016). These arts-based methodologies are proposed to be especially effective for children with ASD because they tap into more non-verbal forms of interaction that can foster empathetic communication (Andrea Behrends et al., 2012). Arts-based interventions have also been found to elicit group belonging, and social support in stressed adults (Williams et al., 2018). While Dance Movement Therapy (DMT) has never been employed to benefit parents of children with ASD, DMT has yielded promising results for adults living with mental-health concerns, such as improving stress management, and reducing psychological distress (Bräuninger, 2012a), and improving perceived quality of life (Bräuninger, 2012b). Dance therapy presents a powerful opportunity to foster relational bonds, to express what arises from one's inner experience: to use the body to create outer forms of inner processes, to let go, attune to the present moment, gain new insights, provoke change, find new energy (Leijssen, 2006), and to increase perceived social support which is of utmost importance for ASD caregivers, who likely face a sense of social isolation (Higgins et al., 2005). Furthermore, for parents of a child with ASD, being a part of a DMT group with other caregivers may help to relieve stress, and build resources (e.g. non-verbal

communication) that can enable them to care for and be more responsive to their child's unique needs to a greater extent, which may be of particular importance to parents high in CS. Dance therapy may also be self-expanding for parental caregivers because it opens up a chance to be creative, and presents parents with novel techniques that they can then use in their everyday life with their child, such as communicating non-verbally through movement (Loman & Foley, 1996). Thus, given the potential for DMT to reduce stress, and to strengthen social support, a DMT group for parents of who have a child with ASD may help them to cope in their situation.

Purpose of This Research

The goal of my research was to better understand if interpersonal variables (appreciation, communal strength, responsiveness, self-expansion) can protect well-being among PwPD, their spousal care partners, and parents of a child with ASD, as in the general population.

Furthermore, I sought to evaluate how care partners and PwPD may cope differently, by comparing how these two types of partners fare in terms of personal and relational well-being in order to add to what is known about the relational nature of coping with PD.

Second, this work considered the benefits of an activity that is expected to be self-expanding, dance. Two populations of caregivers were considered, in two different studies. Study 1 investigated PwPD and their care partners, and Study 2 assessed parental caregivers of a child with ASD. In both studies, participants reported their experiences from a dance-based activity that they already participate in (Dancing with Parkinson's for couples coping with PD, and DMT for parental caregivers). All participants completed a one-time online survey, that considered interpersonal variables (e.g. communal strength), personal well-being outcome variables (satisfaction with life, depression, burden for caregivers) and relational outcome

variables (relationship satisfaction, family burden), and were asked to give qualitative feedback on their experiences in a dance-based activity.

Study 1

Predictions and Hypotheses

General Associations

Hypothesis 1. Care partners who report less relationship and life satisfaction, will report more burden (Schrag et al., 2006; Simonelli et al., 2008). When care partners report higher communal strength and self-expansion, they will report less burden and more capability to cope with their partner's problems.

Hypothesis 2. PwPD will report more depression, and less relationship satisfaction than their care partner (Nilsson et al., 2002; Ricciardi et al., 2015)

Hypothesis 3. When spousal care partners and PwPD report higher appreciation, partner-specific communal strength, perceived partner responsiveness, and self-expansion with their partner in general, this will be associated with higher life and relationship satisfaction, for one's self and their partner (Y. Kim et al., 2007; Lemay et al., 2007; Muise et al., 2019).

Dance-specific associations

Hypothesis 1. For couples that dance together, when both spousal care partners and PwPD report higher communal strength specifically within dance class, this will be associated with higher reports of relationship satisfaction. Furthermore, when one's partner reports being more responsive to their movement during the dance class, this will be associated with higher reports of relationship satisfaction.

Hypothesis 2. When spousal care partners and PwPD report dance as a self-expanding activity to do with their partner, this will be associated with higher reports of more positive emotions in the class towards their partner, and higher reports of relationship satisfaction.

Hypothesis 3. When care partners report attending the dance class for communal reasons (e.g. I attend DwP because I think my presence helps my partner) they will report more burden relief from DwP.

Hypothesis 4. Comparisons between couples who dance vs. do not dance together

- a) Partners of couples who dance together will on average, be less depressed and have greater life and relationship satisfaction compared to partners in couples where the spousal care partner does not attend the dance class.
- b) Spousal care partners who attend dance class will be stronger in CS than partners who do not attend DwP.
- c) PwPD who dance with their partners will find the dance class more enjoyable than those who attend alone (Kunkel et al., 2018). This association may be related to the extent of partner interaction, and one's feelings towards their partner within the dance class (e.g. frustrated, connected, etc.)

Methods

To assess the variables of interest, PwPD and their spousal care partners, who either attend DwP with them or not, were surveyed on Qualtrics, an online survey platform.

Participants and Procedure

Couples were recruited from ongoing DwP classes around Canada and the USA. Couples were eligible to participate if they were in an exclusive, monogamous relationship where one partner had PD and had attended DwP for at least one term, and the other partner

considered themselves a primary caregiver for their spouse, and had either attended DwP for one term, or not at all. Both partners had to be within the ages of 45-95, been together for at least 2 years, and be able to independently answer survey questions. DwP teachers were contacted via email to verbally promote the study in class, and research assistants also attended classes to recruit participants with flyers (see Appendix A to see recruitment poster). Couples who were interested were asked to email the researchers and to complete some eligibility questions via email. Once screened for the eligibility criteria, participants were sent unique survey links to complete the online survey. Participants who completed the survey were entered to win 1 of 4 \$25 gift-cards. In total, 44 individuals completed the survey. 12 full couples who danced together (One care partner, and one PwPD) and 8 couples in which the care partner did not dance completed the survey. 13 couples were from the Greater Toronto Area, and 7 couples were from New York City. Additionally, 4 care partners also completed the survey, but their spouses with PD did not participate due to cognitive/motor challenges that prevented them participating independently.

Participants ranged in age from 48 to 92 ($M = 73.84$, $SD = 8.2$) and had been in their current relationship for 7 to 63 years ($M = 44.80$, $SD = 13.57$). Most participants were married (95%) with 2.3% common-law, and 2.3% living together. All participants were in heterosexual relationships, except one care partner who was homosexual whose male partner with PD did not complete the survey. In total, half of the participants were male, and half were female. Participants with PD had an average score of 1.24 ($SD = .67$) for non-motor aspects of experiences of daily living, and 1.15 ($SD = .60$) for motor aspects of experiences of daily living, where 0 represents no problems and 4 represents severe challenges as a result of PD.

Adapted Dance

Participants with PD recruited for the present study must have attended a Dancing with Parkinson's class (Canada) based on the Dance for PD model (DanceforPD, 2017) or Dance for PD class (USA). DwP is taught by many different certified dance instructors across Canada, and each class is typically 1-hour in duration. DwP classes range in price for participants from \$5-\$10 a class, and care partners can attend for free with their partner. Some component parts of every DwP session include warm up, upper and lower body mobility movements, improvisation, mirroring, and choreography. For a detailed sample class, see Appendix B.

General Measures Completed by Both Partners

(To see all survey items, see Appendix C)

Demographics. All participants were asked a variety of demographics questions including their age, gender, relationship status and duration of relationship. The partner with PD also completed portions of the motor and non-motor subscales of the MDS-UPDRS questionnaire (Goetz et al., 2008) which provides the gold-standard clinical marker of severity of motor and non-motor symptoms (e.g. sleep disturbance, eating, daily living tasks). Disease severity was considered in analyses.

Interpersonal variables.

Appreciation in Relationships. We assessed sense of appreciation among couples using parts of (Gordon et al., 2012) scale. The present study selected 2 -face valid items in which participants were asked to rate how appreciative they are of their partner are on a 7-point Likert scale from 1 = "strongly disagree" to 7 = "strongly agree": "I often tell my partner how much I appreciate him/her", and "I appreciate my partner".

Communal Strength: partner-specific. We assessed partner-specific communal strength using Mills et al. (2005) 10-item scale that assesses a person's general motivation to be responsive to their partner's needs. Items were rated on a 11-point Likert scale, from 0 = "not at all", to 10 = "extremely" and included "How happy do you feel when doing something that helps your partner?".

Perceived Partner Responsiveness. We assessed how responsive partners perceived their spouse to be by using 3 face-valid items from (Reis, 2003) perceived partner responsiveness measure, that assesses how responsive a person feels their partner has been to their needs to be validated and understood. Items were rated on a 5-point scale, from 1 = "not at all" to 5 = "very much so". An example item is "My partner makes me feel cared for."

Self-Expansion. We assessed general self-expansion with one's partner using (Lewandowski & Aron, 2002) 6-item scale, that assesses a person's sense of novelty/ expanding of self with their partner. Items were rated on a 7-point scale, from 1 = "not very much" to 7 = "very much". An example scale item is "How much does being with your partner result in you having new experiences?".

Outcome measures.

Relationship Satisfaction. We assessed relationship satisfaction using (Funk & Rogge, 2007) Couples Satisfaction Index. This 16-item scale is comprised of three subscales each scored differently. Two of these scales were included in the present study. The first section asked participants to rate their feelings towards their partner (e.g. extent of happiness) and the second section was statements such as "our relationship is strong", scored on a 6-point scale from 0 = "never" to 5 = "all of the time".

Depression. We assessed depressive symptoms using the Geriatric Depression Scale (Yesavage, 1988) This 15-item measure was developed specifically for geriatric population, with concise, simple statements to which respondents choose either “YES” or “NO” to 15 statements, such as “Do you feel that your life is empty?”, where yes would be indicative of depression.

Satisfaction with Life. We assessed satisfaction with life using (Diener et al., 1985) 5-item scale, which assesses how satisfied individuals are with their life circumstances. Items were rated on a 7-point Likert Scale from 1 = “strongly disagree”, to 7 = “strongly agree”. An example scale item is “I am satisfied with my life”.

Additional Questions Only for Couples Who Attend DwP Together

Dance-Related Questions. For couples who indicated at the beginning of the survey that they attend dance classes together, they were asked some basic questions about their experience in the dance class such as: how long they have been attending (# of months and years), which location(s) they attended, and their favourite portion of the class (e.g. warm up, improv, choreography). Partners were also asked to indicate on a 5-point scale from 0 = “never”, to 4 = “always” the extent to which they sit together, do partnered dances together, and partner with each other for improvisational activities such as mirroring.

Dance-Specific Communal Strength. To assess how communal strength may affect dance class, the partner-specific communal strength scale (Mills et al., 2004) was adapted in 2 ways to be dance specific. First, we asked about communal motivation during the dance class, for both PwPD and caregivers who attended the dance class. For example, “How happy do you feel when doing something your partner enjoys in the dance class?”. Second, this scale was adapted to assess caregivers’ communal motivation to attend DwP with their partner. An

example item is: “To what extent do you attend the dance class with your partner because you think your presence in the class helps them?”.

Dance-Specific Responsiveness in Movement. To investigate how responsive participants perceive themselves to be in movement, Fuchs and Koch’s (2014) embodied intersubjectivity scale was used. This 10-item measure was designed to assess perceived responsiveness/ empathetic understanding through interactive movement with another person. The present study utilized 4 of the scale items, which are on a 6-point scale from 0 = “applies not at all” to 5 = “applies exactly”. An example scale item is: “through joint movement with my partner, a connectedness arises” (Fuchs & Koch, 2014).

Dance-Specific Self-Expansion. To assess how self-expanding dance is for participants, the generic 7-point self-expansion scale (Lewandowski & Aron, 2002) was also adapted to be dance-specific in two ways. First, all people with PD who attend DwP were asked “how much does attending the dance class expand your sense of kind of person you are”. Second, for couples that dance together, this scale was partner specific. For example: “How much does attending the dance class with your partner expand your sense of the kind of person you are?”.

Feelings Towards One’s Self and Partner in the Dance Class. We assessed how much positive and negative affect participants felt in general in the dance class. Participants were asked to rate the extent of 4 positive feelings (joyful, connected, relaxed, satisfied) and 3 negative feelings (frustrated, resentful, stressed) on an 8-point scale from 1 = “not very much” to 7 = “very much. Participants were also asked to rate how much they felt these emotions towards/about *their partner* in the dance class if they attended with their spouse.

Open-ended Question. We assessed participant’s overall feedback/ experience with DwP with a question at the end of the survey, “Please let us know if you have any additional

comments or thoughts on the survey below”. This optional question was asked to elicit some more descriptive, qualitative data.

Outcome Measures Only for Care Partners

Burden Inventory General and Dance-specific. We assessed caregiver burden for all care partners using The Maslach Burnout Inventory, (Maslach et al., 1997), a 6-item scale that evaluates how frequently caregivers feel burdened from their tasks, as well as how effectively a caregiver feels they are able to cope with their spouse’s problems. Items were rated on a 7-point scale, ranging from 0 = “never” to 6 = “everyday”. An example item is “I feel emotionally drained from caring for my partner”. This burnout inventory was also adapted to be dance specific for care partners who attend DwP with their partner. An example of this adapted scale is: “I deal more effectively with the problems of my partner after attending DwP.”

Behavioural measures. Care partners that attend DwP were also asked to rate two future behaviours from 0 = “strongly disagree”, to 4 = “strongly agree”: if they would recommend to a friend in their situation to attend DwP, and if they would attend another session, if offered.

Data Analysis

Data were restructured to be dyadic by using David Kenny’s data restructuring app, which is available at: <https://davidakenny.shinyapps.io/ItoP/>. We used correlations and linear regression analyses to test our predictions about correlates and predictors of care partner burden. The caregiving burden scale was considered overall, and also a subscale of positive coping items were used in regression analyses.

To test our dyadic predictions, we used multilevel modeling using mixed models in SPSS, guided by the actor-partner independence model (Kenny et al., 2006). We tested two-level

models, with each participant nested within their dyad. We treated dyads as distinguishable (PwPD and care partner), and thus we had separate intercepts for PwPD and care partners. Each model includes both partner's reports of the predictor variables (e.g. communal strength) and all predictors were grand mean-centered, aggregated, and the models were run separately for each predictor, and outcome variable that we expected associations for. The coefficients are unstandardized betas (b) and represent changes in the outcome variable for every one-unit change in the predictor from the mean of the sample.

For all analyses related to dance variables, a subset of the data was used, that included participants who attended DwP. For general dance questions (e.g. favourite part of the class), all PwPD were included, and care partners who attend dance. For partner-specific dance questions (e.g. self-expansion with one's partner in dance), only the 12 couples who attend dance together were included. We looked for mean differences between PwPD and care partners separately, and then analyzed associations between dance variables and outcome variables (e.g. relationship satisfaction) with Pearson correlations in SPSS with both partner types combined.

Results

Descriptive Statistics

Average Levels of Key Variables and Differences Between Care Partners and PwPD. Overall, the descriptive statistics for the interpersonal variables show that these couples are functioning quite well (see Table 1). Both PwPD and CP are quite appreciative of their partner, are communally motivated to meet their partner's needs, and perceive their partners to be responsive, and self-expanding, as these means are far past the midpoints of the scales. In terms of relationship-specific outcome variables, relationship satisfaction is relatively high on average, being past the midpoint of the scale, $M = 40.50$ ($SD = 7.50$), out of a total of 51 with

higher scores being indicative of greater relationship satisfaction. PwPD were not significantly less satisfied in their relationship, compared to their care partner, contrary to our expectation, $p = .556$. For personal well-being measures, satisfaction with life is fairly high on average, $M = 5.13$, ($SD = .91$) on a 1-7 scale, and on average participants reported low symptoms of depression, ($M = 2.79$, $SD = 2.38$). We had predicted that in general, PwPD would be more depressed compared to their care partner. Based on the means, PwPD did on average, have slightly higher depression scores, $M = 2.86$, ($SD = 2.52$) compared to care partners, $M = 2.75$ ($SD = 2.33$) but this difference is not significant, $p = .830$. Similarly, 6 care partners, and 5 PwPD scored between 5-8 on the GDS, which is indicative of mild depression and thus in our sample, PwPD did not report significantly higher depression than their care partner. However, PD severity was quite low among this sample, as on average symptoms were reported as “slight”, which may explain why more differences between CP and PwPD were not found.

Inferential Statistics

Care Partner Correlates of Burden. We predicted that when care partners were less satisfied in their relationship, and in life that they would report more caregiving burden, (see Table 2). Indeed, relationship satisfaction was significantly negatively correlated with care partner burden, $r = -.608$, $p = .003$ as well as life satisfaction, $r = -.449$, $p = .028$. Communal strength was not significantly associated with less burden, contrary to our expectations. However, when care partners reported that their relationship was more self-expanding, they reported significantly less burden, $r = -.452$, $p = .027$ and correspondingly, self-expansion in care partners predicted being able to cope more effectively with their spouse’s problems, $b = .621$, $p = .004$.

Table 1*Descriptive Statistics of Interpersonal and Outcome Variables for All Couples*

	Scale	Partner with PD (N=20)		Care Partner (N=22)	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
PD Non-motor challenges	0-4	1.24	.67	-	-
PD Motor challenges	0-4	1.15	.60	-	-
Perceived Partner Responsiveness	1-5	4.55	.54	4.54	.56
Communal Strength	0-10	8.62	1.14	8.78	.90
Self-Expansion	1-7	5.59	.91	5.37	1.0
Appreciation	1-7	5.93	1.16	5.43	1.16
Relationship Satisfaction	/51	40.70	8.3	40.33	6.9
Satisfaction with Life	1-7	5.17	.91	5.10	.93
Depression	/15	2.86	2.51	2.75	2.32
Caregiver Burden	0-6	-	-	1.82	.73

Table 2*Correlations of Key Variables for all Couples by Partner Type*

Variable	1	2	3	4	5	6	7	8
1. Communal Strength	1	.216	-.253	.281	.555*	.161	-.237	-
		-.104	.012	.153	.283	.179	-.120	-.395
2. Perceived Partner Responsiveness	-	1	.229	.208	.647**	.157	-.116	-
				.574**	.524*	.704	.141	-.131
3. Self-Expansion	-	-	1	.127	.261	.060	-.032	-
				.443*	.515*	.432*	-.125	-.452*
4. Appreciative	-	-	-	1	.501*	-.067	.221	-
					.547**	.343	.001	-.363
5. Relationship Satisfaction	-	-	-	-	-	1	-.075	-
							-.498*	-.608**
6. Life Satisfaction	-	-	-	-	-	-	1	-
								-.449*
7. Depression	-	-	-	-	-	-	-	1
8. Caregiver Burden	-	-	-	-	-	-	-	-

Note: Correlations for partners with PD (N=20) are bolded, and correlations in plain text are for Care Partners (N=24)

* $p < .05$. ** $p < .01$

Inferential Statistics

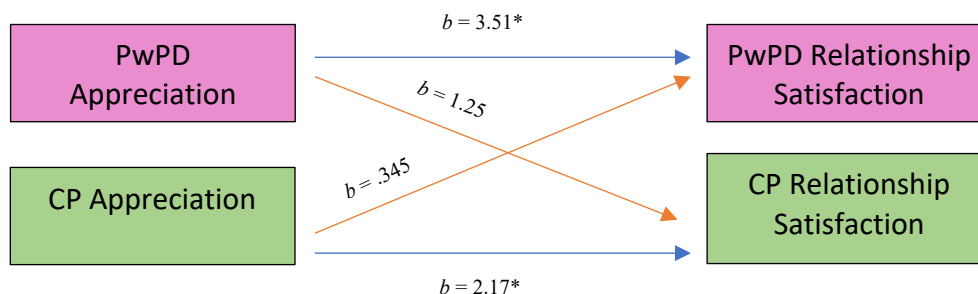
Tests of Actor and Partner Effects of Interpersonal Variables on Relationship

Satisfaction. We predicted that when PwPD and care partners reported higher appreciation, communal strength, perceived partner responsiveness, and self-expansion that they would report higher relationship satisfaction, and that one's scores would impact their own outcomes (actor effects), as well as their partner's outcomes (partner effects), see Table 3.

Appreciation. For both care partners and partners with PD, when they reported being more appreciative of their partner, they reported higher relationship satisfaction, as predicted, see Figure 1. However, no partner effects were found, such that one's own degree of appreciation for their partner did not predict their partner's relationship satisfaction.

Figure 1

Actor and Partner Effects of Appreciation for one's partner on Relationship Satisfaction



Note. $*$ = $p < .05$. PwPD = partner with PD, CP= care partner.

Table 3

APIM Analyses: Effects of Communal Strength, Self-Expansion, Perceived Partner Responsiveness and Appreciation for one's partner on Relationship Satisfaction

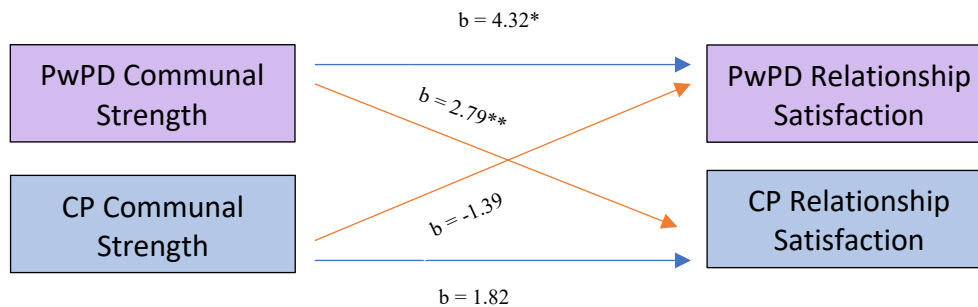
	<u>PwPD's Relationship Satisfaction</u>			<u>Care Partner's Relationship Satisfaction</u>		
	<i>b</i> (SE)	<i>t</i>	CI []	<i>b</i> (SE)	<i>t</i>	CI []
PwPD Communal Strength	4.32(1.49)	25.24*	[1.17, 7.48]	2.97(.88)	3.37**	[1.11, 4.83]
CP Communal Strength	-1.39(1.84)	-.756	[-5.30, 2.50]	1.82(1.09)	1.67	[-.480, 4.12]
PwPD Self-Expansion	2.09(1.69)	1.24	[-1.47, 5.66]	-1.43(1.32)	-1.08	[-4.23, 1.36]
CP Self-Expansion	5.75(1.76)	3.26*	[2.02, 9.47]	3.05(1.38)	2.20*	[.126, 5.98]
PwPD Perceived Partner Responsiveness	9.78(3.39)	2.89*	[2.63, 16.93]	2.01(2.57)	.783	[-3.41, 7.44]
CP Perceived Partner Responsiveness	.455(4.67)	.097	[-9.41, 10.32]	6.07(3.55)	1.71	[-1.42, 13.56]
PwPD Appreciation	3.51(1.59)	2.20*	[.128, 6.90]	1.25(.98)	1.28	[-.821, 3.32]
CP Appreciation	.345(1.32)	-2.61	[-2.46, 3.15]	2.17(.811)	2.86*	[.456, 3.89]

Note. Beta values are grand-mean centered coefficient estimates. PwPD = partner with PD (N = 20), CP = care partners (N = 20). * $p < .05$. ** $p < .01$

Communal Strength. When PwPD reported higher communal strength, they reported significantly higher relationship satisfaction, and so did their care partner. However, when care partners reported higher communal strength, this was not significantly related to greater relationship satisfaction for themselves, or their partner with PD as expected. This finding indicates that perhaps the communal strength of the partner with PD is particularly important for how satisfied the care partner is in the relationship.

Figure 2

Actor and Partner Effects of Communal Strength on Relationship Satisfaction



Note. * = $p < .05$. PwPD = partner with PD, CP= care partner.

Partner Perceived Responsiveness. As predicted, when PwPD perceived their partner to be more responsive, they reported significantly higher relationship satisfaction, but this effect was not significant for care partners. There were no significant partner effects of perceived partner responsiveness.

Self-Expansion. Lastly, when care partners reported higher self-expansion, they reported higher relationship satisfaction, and their partner with PD also reported higher relationship satisfaction. This indicates that when care partners' experience more self-expansion, they are more satisfied in the relationship, as well as their partner with PD.

Dance Descriptives.

Of the 20 full couples who completed the survey, 12 couples attended DwP together, and they had been attending DwP for half of a year to 13 years ($M = 3.94$, $SD = 3.33$). The majority of these couples (65%) attended DwP once a week, 20% attended more than once a week, 8.6% attended once a month and 5.7% attended less than once a month.

In general, all participants that attended DwP seemed to enjoy it and experience a high degree of positive emotions in the class: connectedness, joyfulness, relaxation and satisfaction ($M = 5.72$, $SD = 1.06$) and a low degree of negative emotions: resentfulness, frustration and stress ($M = 1.51$, $SD = .90$), see Table 4. Similarly, partners that danced together reported that they felt strong positive emotions towards their partner in the dance class, and low degrees of negative emotions, with PwPD feeling slightly more resentful or frustrated with their partners ($M = 2.30$, $SD = 1.98$) than care partners ($M = 1.40$, $SD = .65$), but not significantly, $p = .146$.

Furthermore, when participants were asked to report their favourite part of DwP session, 28% of participants found standing choreography the most enjoyable, 22% seated choreography, 19% chose “other” and wrote variations of “all of class!.. all of it”, 16% partnered activities, 6% improvisation, 3% mirroring, 3% warm up, and 3% across the floor. Typically, within a DwP class, there is at least 1 or 2 new choreographies taught each week, which is an opportunity for dancers to learn something new, to a new piece of music and spatial organization. This information is interesting as it shows that these participants really enjoyed learning new things, challenging themselves to memorize movement choreography, and also appreciate the variety of a whole class. If only couples who dance together were looked at, standing choreography was still the most frequent response, reported by 27% of participants and partnered activities were the favourite part of class for 15% of respondents.

Table 4*Descriptive Statistics: Dance Variables for Couples that Attend Dancing with Parkinson's Together*

	Scale	Partner with PD (N=12)		Care Partner (N=12)	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Dance Responsiveness to Partner	0-4	3.06	1.33	3.27	1.21
Dance Communal Strength	0-10	8.00	1.67	8.67	1.11
Care Partner Communal Motivations to Attend DwP	0-10	-	-	9.08	.83
Interaction with Partner During Dance	0-10	2.75	1.11	2.69	1.68
Dance Self-Expansion with Partner	1-7	5.27	1.25	5.27	1.12
Dance Positive Affect	1-7	5.71	1.13	5.57	.95
Dance Negative Affect	1-7	1.59	1.06	1.39	.53
Dance Positive Affect with Partner	1-7	5.74	.97	6.00	.88
Dance Negative Affect with Partner	1-7	2.30	1.94	1.40	.65
Care Partner Burden Reduction from DwP	0-6	-	-	1.69	.73

Table 5

Correlations of Key Interpersonal Variables, Dance variables and Outcome variables for Couples who Dance Together

Variable	1	2	3	4	5	6	7	8
1. Dance Communal Strength	1	.247	.099	.543**	-.043	.532**	.386	.241
2. Partner Responsiveness in Dance	-	1	-.139	.349	-.264	.444*	.373	.534**
3. Dance Self-Expansion with Partner	-	-	1	.419*	.132	.401	.373	-.151
4. Dance Positive Affect with Partner	-	-	-	1	-.145	.529**	.545**	.185
5. Dance Negative Affect with Partner	-	-	-	-	1	-.135	-.319	-.045
6. Relationship Satisfaction	-	-	-	-	-	1	-	-.028
7. Satisfaction with Life	-	-	-	-	-	-	1	.004
8. Extent of Partner Interaction in Dance	-	-	-	-	-	-	-	1

Note. N = 24: 12 PwPD and 12 Care Partners combined. * $p < .05$. ** $p < .01$

Associations between Dance Variables and Well-being Outcomes (see Table 5).

Communal Strength During Dance. We predicted and found that when spousal care partners and PwPD report being more communally motivated while participating in dance class (e.g. feeling happy when doing something they know their partner enjoys in the dance class) they experienced greater relationship satisfaction, $r = .532, p = .007$.

Partner Responsiveness During Dance. Furthermore, one's own relationship satisfaction was significantly correlated with their partner's report of degree of responsiveness to them in movement (e.g. able to understand their partner's needs with movement) $r = .444, p = .030$. This suggests that when one's partner was more responsive to them in dance, they were more satisfied with their relationship, which is in alignment with previous findings on responsiveness in general (Lemay et al., 2007). Correspondingly, the more partners reported interacting with each other during the dance class, the more responsive they reported being to their partner's movement, $r = .534, p = .007$, but contrary to our expectations, more partner interaction was not significantly associated with greater relationship satisfaction, $r = -.028, p = .897$. Given past research that indicates PwPD are less empathetic to their partners, we also considered how PwPD and care partners differed in responsiveness in movement. We did find that care partners were slightly more perceptive to their partner's desires with movement ($M = 3.27, SD = 1.22$), than PwPD ($M = 3.06, SD = 1.33$), but this difference was not significant, $p = .693$.

Self-Expansion with One's Partner in Dance. DwP was fairly self-expanding for all participants that attended. For PwPD who attended alone, they rated DwP as self-expanding, with scores ranging from 3.33 to 7.00 on a 1-7 scale, with 43% of participants rating dance self-expansion a 6 or 7 ($M = 5.46, SD = 1.16$). When couples attended together, they also found DwP self-expanding to do with their partner specifically, with scores ranging from 3.00 to 7.00, with

30% of participants rating it 6 or 7 ($M = 5.27$, $SD = 1.16$). Reports of how self-expanding DwP was were not significantly associated with how many years individuals had been attending DwP, $r = .097$, $p = .675$. As predicted, self-expansion with one's partner in dance was significantly correlated with more positive affect towards one's partner in dance, $r = .419$, $p = .047$ but self-expansion from the dance class was not related to broader reports of relationship satisfaction or satisfaction with life. However, when participants reported higher positive affect with their partner in dance, they reported being more satisfied with their life, $r = .545$, $p = .007$ and with their relationship, $r = .529$, $p = .009$.

Care Partner Motivations to Attend DwP and Burden. Our third dance-related hypothesis for this sample was that when care partners report being motivated to attend DwP for communal reasons, they would report more burden relief from DwP. The care partners in our sample appeared to attend DwP for highly communal reasons ($M = 9.08$, $SD = .83$ on a 0-10 scale), such as "I attend DwP because I feel my presence helps my partner" but they did not report much perceived burden relief from attending DwP ($M = 1.69$, $SD = .73$) on a scale from 0-6, with a higher number representing more burden relief. So, it appears that in this sample, care partners attended DwP not as much for their own benefit, but rather for their PwPD.

Care Partner Behavioural Measures. We also asked care partners some behavioural measures relating to the dance class, and they reported that overall, they did enjoy the dance class ($M = 2.78$, $SD = .44$) with 0 representing "not at all" and 3 representing "very much". Care partners who attended DwP also reported that they would recommend a friend in their situation who had a spouse with Parkinson's to attend a dance class like this with their partner, $M = 3.60$, $SD = .69$, and that they would on average, attend again if another session was offered, $M = 2.44$,

$SD = .882$, where 0 represented “strongly disagree” on the scale and 4 represented “strongly agree” for both of these items.

Differences Between Couples Who Dance and Do Not Dance Together. Our last set of hypotheses for this study was pertaining to anticipated differences between couples and who dance together vs. do not dance together, see Table 6. On average, couples who attended DwP together had higher relationship satisfaction on average, $M = 42.17$, $SD = 6.19$ than couples where only the PwPD dances, $M = 40.18$, $SD = 8.40$, however these means are not statistically different, $p = .594$ see Table 6. Furthermore, contrary to our prediction, satisfaction with life ($M = 5.20$, $SD = .96$) was higher on average but not significantly higher for couples who dance together than couples where the care partner does not dance, $M_{SwL} = 5.33$, $SD = .773$, $p = .344$. Depression was also higher in couples that dance together ($M = 2.83$, $SD = .25$) were actually higher on average for couples who dance together compared to couples where the care partner does not dance ($M_{depression} = 1.93$, $SD = .18$), but not significantly, $p = .188$. We also hypothesized that care partners who attend DwP would be higher in general communal strength than care partners who do not attend. We did not find support for this hypothesis, as both types of care partners on average, scored 8.7 on general communal strength. Lastly, we expected that PwPD who dance with their partners will find DwP more enjoyable than those who attend alone. On average, PwPD who attend DwP with their spouse do report experiencing slightly more positive emotions, $M = 5.89$, $SD = 1.09$ than PwPD who do not dance with their spouse $M = 5.43$, $SD = 1.21$, but this comparison is not significant, $p = .400$. Surprisingly, PwPD who attend dance with their spouse also reported experiencing a higher degree of negative emotions $M = 1.82$, compared to PwPD whose spouses do not dance, $M = 1.25$, although this comparison is not significant, $p = .250$.

Table 6*Mean Comparisons between PwPD who have CP who Dance vs. Do Not Dance*

	Couples that Dance Together	Couples that Do not Dance Together	PwPD that Dances with their Spouse	PwPD that Dances without their Spouse
Relationship Satisfaction	42.167	40.167	-	-
Satisfaction with Life	5.20	5.33	-	-
Depression	2.83	1.93	-	-
Positive Affect in Dance	-	-	5.895	5.437
Negative Affect in Dance	-	-	1.819	1.250

Note. No comparisons of means are significant.

Qualitative Findings

When participants were given a chance to provide any additional feedback regarding their experience, two PwPD and 7 care partners answered this optional qualitative question (to see all responses, see Appendix D). Two key themes that emerged from these responses were: the impacts of dance for one's well-being, and the complexities of researching this population.

Well-being. Three care partners who attend DwP with their spouse mentioned how positive dancing has been for them as couples. One expressed the positive emotional impact of DwP: "Dance for PD is the happiest part of our week". Another care partner expressed the social benefits they have experienced: "Dance for PD is more than a dance program. I have benefitted by attending class and making new friends. I have been accepted by my fellow dancers and have gained much from the social aspect of dance". Lastly, another care partner expressed how dancing with her spouse has brought them together as a couple: "I feel that it is good that you have this survey as it helped me to realize how happy we are with each other and that through dance it makes us closer. I have danced since the age of 2 and I am so happy that we as a couple can make a difference with the dancing with Parkinson's program."

One other care partner, whose partner did not answer the survey due to challenging PD symptoms had an interesting point about enjoying the DwP class, *without* his partner “A point that has been overlooked, is that, as the caregiver I hand over my partner to the volunteers, giving me "time off" to concentrate on the dancing myself without having to care for my partner, while my partner socializes with the volunteers. This is one of the times I don't have to worry/be concerned as the caregiver!” This is a noteworthy comment, that is supported by the data, as no strong relationships were found between more partner interaction in the dance class, and more enjoyment of DwP, or relationship satisfaction.

Complexities. A second theme that emerged from these comments was the multifaceted challenges in the lives of these couples. Notably, one care partner, whose partner with PD was unable to participate in the survey due to cognitive challenges expressed how their answers to this survey would have been quite different, before their partner’s symptoms progressed: “At times I was confused if I should answer the questions looking at our whole life together or our life since PD entered our space! Naturally our life has changed, especially since dementia is part of our PD journey. As the full-time caregiver, I am sure I am looking at life through different lenses than my partner.” This is important feedback because it highlights the importance of seeing how relationship quality may change over time for these couples, and the need to further investigate how care partner well-being may be doubly impacted if their spouse is diagnosed with PD as well as another disorder, such as Dementia. Lastly, a partner with PD indicated that other life factors, like financial stability were impactful in their responses: “Contentment can also be affected by financial worries, quite apart from romantic feelings. This survey leaves this factor out”. Thus, it may be beneficial in the future to consider how PD may affect financial

strain and/or how stress is compounded in a relationship for both partners, dependent on one's financial security.

Discussion

Maintaining relationship satisfaction for couples coping with neurodegenerative disorders is challenging (Martinez et al., 2018; Ricciardi et al., 2015), as PwPD have accelerating symptoms, and care partners experience the burdens of their new caregiving role (Y. Kim et al., 2007). Despite these challenges, it is essential to note that there do seem to be interpersonal factors (e.g. appreciation) and/or interventions (self-expanding activities) that can enable couples to maintain personal, and relational well-being (Greenwell et al., 2014; Mavandadi et al., 2014; Muise et al., 2019). The findings from the present study indicate that at least when PD symptoms are mild, couples who have been together for decades can still have fairly high relationship satisfaction. Based on the midpoints of the scales, in the present sample, the average PD symptom severity was low, and relationship satisfaction was quite high. We also did not find any significant differences in relationship satisfaction between PwPD and their care partners, as in previous work (Ricciardi et al., 2015), in which PwPD experienced lower relationship satisfaction than their care partner. In our present sample, participants scored low on average on the Geriatric Depression Scale, as well as the UPDRS Parkinson's symptom rating scale, and thus, it is possible that this restriction of range in participant's results prevented us from replicating these past effects. This might have been impacted by our eligibility criteria that all participants had to complete the survey independently, online, without assistance from their spouse. There were 5+ care partners who were interested in completing the present survey, but due to their partner's severity of PD symptoms, their PwPD was not able to complete the survey

independently, and therefore was ineligible. It is possible, that had data been obtained from these PwPD with more progressive symptoms, we may have found these expected associations.

Communal Strength Theory and Responsiveness

In terms of our key variables of interest, these results provide preliminary findings that expand what is known about how both partners experience personal and relational challenges as a result of being diagnosed with PD. Our results with this clinical sample did echo previous work on the impact of interpersonal factors on personal and relational well-being outcomes. In the general population, one's degree of communal strength has been associated with their own greater relationship satisfaction, as well as one's partner's relationship satisfaction (Le et al., 2018). In our sample, we did find that when partners with PD had more communal strength, they were more satisfied in their relationship, as well as their care partner being more satisfied, but when care partners reported more communal strength, they did not report being more satisfied in their relationship. These findings show that for couples coping with PD, when the partner with the diagnosis is more communal, this has a positive impact on the care partner's relationship satisfaction, because perhaps despite their caregiving duties, their relational needs are being met. While our present study did not consider unmitigated communion (Fritz & Helgeson, 1998), this could be investigated in future research as it is possible that care partners may not experience the benefits of being communal because they are caring for their partner to such an extent that they are neglecting their personal needs (Le et al., 2018).

For perceived partner responsiveness, we found that when PwPD perceived their care partner to be more responsive, they were more satisfied in their relationship. This finding supports previous work (Le et al., 2018; Lemay et al., 2007) and extends it by finding similar effects in a clinical population, in which care and the types of needs which require responsive

attention might be imbalanced. So, it appears that even when partner roles change due to neurological conditions, perceived partner responsiveness is still an important factor in maintaining relationship satisfaction.

Furthermore, we were able to expand communal strength theory by considering communal motivation and responsiveness within a particular activity: dancing with one's partner. We found that when partners were more communally motivated in their participation in the dance class, they reported higher relationship satisfaction, and when partners reported more interaction with their spouse in dance class (e.g. sitting together, doing partnered dances together) this was associated with one's partner's report of being more responsive to their spouse's movement. Importantly, when one's partner was more responsive to their movement, this was associated with more relationship satisfaction for the perceiver. However, we cannot specify the direction of these effects: perhaps the inverse direction is also true, such that those couples with higher relationship satisfaction are more communal and responsive with each other in dance class. Future research could attempt to pinpoint the direction of these effects by asking participants to complete daily diary responses and testing if communal strength during dance predicted relationship satisfaction on the subsequent day(s). While we cannot pinpoint the direction of these effects in the present study, these findings are novel because while the literature on communal strength has found consistent support for communal strength being related to relational and personal well-being (Le et al., 2018) these associations have not been considered within the context of developing clinical interventions. For example, based on our findings, more work could consider how different interventions for couples coping with a neurodegenerative condition may focus on communal motivation and partner responsiveness. Additionally, while research on Dancing with Parkinson's has considered how dance affects care

partner's and PwPD's quality of life (Heiberger et al., 2011), no other work to our knowledge has considered the effects of extent of partner interaction within the dance class on broader relationship outcomes such as responsiveness. Our work suggests that interventions such as dance that focus on partner responsiveness may be worth investigating further, especially because as Parkinson's disease progresses, PwPD become less able to express emotional/empathetic responses to their partner, due to impaired facial expression and muscle control (Dujardin et al., 2004) . However, if dance is able to elicit responsive, connectedness between partners, this specific relational benefit should be further investigated. For example, dance classes for couples coping with PD that focus more on responsive movement, mirroring (McGarry & Russo, 2011) and partnered dance could be developed, and compared to the traditional DwP model, to see if PwPD can learn to be more responsive to their partner in movement, and if these gains can be translated into their daily lives, when this takes up a larger portion of the class. While we do suspect that dance presents particularly salient opportunities for partners to display responsiveness, due to the co-creation of choreography, and time spent watching, mirroring and then responding to a partner's movements, dance could be compared to other interventions that might focus on communal motivation and responsiveness, such as expressive writing, or cooking classes that encourage partner collaboration and creation.

Appreciation

Previous work in the general population, and for couples with PD has indicated that gratitude and/or being appreciative were important factors to maintain relationship satisfaction (Gordon et al., 2012; Y. Kim et al., 2007; Mavandadi et al., 2014). This relationship was found in our sample, such that one's degree of appreciation for their partner predicted their own relationship satisfaction. Therefore, this finding helps to support previous work (Mavandadi et

al., 2014), and indicates that appreciation does seem to be an important construct that helps to bolster one's own satisfaction in their relationship with their partner. Consequently, appreciation for each other is important for both PwPD and care partners to cultivate even as neurological conditions cause complications, and change the nature of their relationship, and roles within that relationship (caregiver and care receiver).

Self-Expansion

Lastly, self-expansion was considered due to previous work which has found self-expansion to be positively associated with relationship satisfaction (Muisse et al., 2019). In our sample, when care partners reported that in general, their partner provided them with opportunities for self-expansion, they were more satisfied in their relationship, and their partner with PD was also more satisfied with the relationship. Furthermore, when partners that danced together rated it as highly self-expanding to do with their partner, they experienced a higher degree of positive affect towards their partner; more joy, connectedness and satisfaction. Together, these findings highlight the importance of couples continuing to provide their partners with opportunities to self-expand, even amidst their partner being diagnosed with PD, as caregivers were more satisfied in their relationship when their spouse provided them with a sense of novelty. Care partners even reported that when their relationship was more self-expanding, they experienced less caregiving burden, and felt more able to cope with their partner's problems. These findings are particularly important as we aim to pinpoint relationship and personal factors that can buffer the negative effects of caregiving. Our findings support previous research which found that self-expansion might help to buffer against negative relationship experiences such as sexual distress, (Raposo et al., 2020) due to the fact that self-expanding activities provide couples with a source of positive emotional capital (Walsh et al., 2017). This is

worth further investigating, to see if the types of negative relationship experiences that can be buffered against by self-expanding activities extend past sexual distress, to caregiving stress. Therefore, if dance is experienced as a self-expanding activity, that is associated with positive emotions for couples coping with PD, it is important to further investigate how dance may help to buffer the burdens of caregiving. While care partners in our present sample did not report much burden relief from attending Dancing with Parkinson's classes, it appears that dancing together as a couple did provide partners with a positive and self-expanding experience.

Study 2

Now, in order to consider the impact of interpersonal variables (communal strength, self-expansion) among a different population of caregivers, parental caregivers who have a child with ASD who attended a different dance intervention were surveyed. As in Study 1, these caregivers also provided their feedback on the dance-based intervention that they took part in: a pilot Dance Movement Therapy (DMT) group for parents.

Predictions and Hypotheses

Hypothesis 1: When parents report more severe ASD symptoms in their child, they will report experiencing higher degrees of burden, and lower life satisfaction (Khanna et al., 2011; Stuart & McGrew, 2009)

Hypothesis 2: When parents report higher degrees of CS and SE, they will report higher degrees of life satisfaction, and lower degrees of burden (Le & Impett, 2015).

Hypothesis 3: Parents will on average, enjoy the DMT intervention, find it self-expanding, and report that it helps to reduce their burdens of caregiving.

Methods

Participants and Procedure

Participants of the Dance Movement Therapy (DMT) group for parents of a child with ASD at Les Grands Ballets, in Montreal QC were notified about the study from the course director, and a researcher attended the group to follow up with interested participants. Parents were sent a survey link to either complete the online questionnaire in English or French, based on their preference. From the 7 parents who participated in the pilot DMT group, 5 parents participated in the survey, that had all attended at least 75% of one term's 10 sessions. Four parents completed the survey in English, and one in French. Four of the participants were female and there was one male. Two of these participants are married, and thus they were reporting on the same child. One parent was single and the remaining two parents were in common-law relationships. On average, parent's relationships were 17.75 years in duration. The parents were on average 47.8 years old. Their children with ASD were 8, 8, 25 and 16 years old. Three parents reported on a male child with ASD, and two parents had a female child with ASD. The children were diagnosed with ASD at ages: three, three, five, and 20 years of age. All five of these parent's children also attended DMT groups for children with ASD at Les Grandes Ballets in Montreal.

Dance Movement Therapy

The DMT group was facilitated by Andrea de Almeida, a registered Dance Movement Therapist (R-DMT) and ran once a week for one-hour duration, for 10 weeks. The focus of this group was to communicate through movement, find grounding and exploration, to relieve stress, and support one another and prevent emotional burdens of caregiving. To encourage attendance from these parents, the class was provided to them for free, by the Public Health Agency of Canada, and a DMT class was offered for their children with ASD at the same time, at the same

location. The DMT sessions typically began with time to focus on breath and stretching to open up and attune with one's own body. Based on the traditional DMT session developed by DMT pioneer Marcia Leventhal, a large portion of time each session was devoted to developing a *theme*, which may emerge from the parent's movement, or verbal statements of how they are feeling. Some example themes that were explored in this group included: feeling heavy, burden, and looking for support. Through group movement, these themes were explored in various ways. DMT props were available for participants to use if the group felt led to use them in a collective manner. For example, the Octaband, which has a circle in the middle, and numerous strips of colourful stretchy fabric extending out from the middle, for dancers to hold, twist, and connect to and was designed to encourage spontaneity, and awareness of others, and has been used in DMT to encourage social support with mothers before (de Valenzuela, 2014) was provided. Furthermore, the "Elastablast" which is a heavy-duty elastic, covered in soft fabric, which was designed to promote group synchrony was also in the studio for parents to use within the group, as well as massage balls for self-soothing, and muscle relaxation. These DMT sessions typically ended with a verbal-sharing of challenges they faced that week, and upcoming perceived trials with their children. These challenges were put into movement, and the group could offer suggestions, and empathy to one another. An example class is provided in Appendix E.

Measures

(To see all survey items for Study 2, see Appendix F)

Demographics. All participants were asked their age, relationship status and duration, and which gender they identify as, as well as their child's age, and gender, what age their child was diagnosed with ASD, and if they have any other children on the spectrum and/or with other developmental disorders.

ASD symptom severity. We assessed children's autism symptom severity with the Developmental Behavioural Checklist (Taffe et al., 2007). This is a 24-item scale that asked parents to rate the severity of their child's ASD symptoms, based on the last 6 months from 0 = "not true of their child", 1 = "somewhat or sometimes true of their child", or 2 = "very true" or "often true of their child". Some example statements are: "refuses to go to school, activity centre", "grinds teeth", "repeats the same word or phrase over and over".

Interpersonal variables. We assessed communal strength using the same Communal Strength (Mills et al., 2004) and Self-Expansion (Lewandowski & Aron, 2002) measures from Study 1, however instead of being framed towards one's *partner*, they were asked to keep *their child* in mind. For example: "how readily can you put the needs of your child out of your thoughts", "how much does being the parent of your child result in you having new experiences".

Outcome variables.

Caregiver Burden. We assessed caregiver burden using the Caregiver Strain questionnaire (Brannan et al., 1997). This 21-item scale was developed specifically for parents of a child with a developmental/behavioural disorder and takes into account caregiver as well as overall family functioning/burden. The scale is comprised of statements and participants were asked to rate how much of a problem various things were in their personal life/family, from 1 = "not at all", to 5 = "very much so a problem". An example scale item is "disruption of family social activities".

Enjoyment and Experience of DMT. Participants were asked to respond to an open-ended question: "Please describe the parts of the dance therapy session that you find most enjoyable? (describe your favourite components or list the things you enjoy the most)". They

were also asked on a 5-point Likert scale how much they enjoyed attending the DMT sessions every week, and to what extent they felt various emotions within and after a typical session, on a 8-point scale, from 1 = “not very much” to 7 = “very much”. For example, joyful, connected, frustrated. Lastly, as in Study 1, the self-expansion measure was adapted to be dance-specific, to assess how self-expanding DMT was as an activity to do with other caregivers.

Burden Relief from DMT. To assess if DMT enables parental caregivers to feel a reduction in caregiving burdens, the same burnout inventory (Maslach et al., 1997) from Study 1 used was adapted to be dance-specific but framed towards their child. For example, “I deal more effectively with the problems of my child after attending a dance therapy session.”

Satisfaction with Life. To assess satisfaction with life, These parents were also asked the same Satisfaction with Life scale (Diener et al., 1985) as in study 1.

Behavioural Measures. Parents were asked how likely they would be to recommend that other PC in their situation attend this group, and how likely they would be to attend another session if offered on a 5-point scale from 1 = “strongly disagree” to 5 = “strongly agree”. Lastly, participants were asked: “please share any other comments regarding your personal experience/thoughts on the dance therapy program” to provide some more experiential data.

Data Analysis

We analyzed the quantitative data using statistics in SPSS and graphing in Excel. The sample size is small (N=5) and thus, lack of power prevented the use of any inferential models to be tested for assessment measures. Therefore, the analytic strategy for this study included a combination of alternative methods. First, means and standard deviations for all measures were calculated, for overall scales and also for each parent individually. We identified scales/ scale items with particularly high or low scores to investigate specific scale items further.

Second, correlations between key variables that were predicted to be associated (e.g. ASD severity and parent burden) were calculated and graphed to consider these relationships, however the correlations should be interpreted with caution due to the small sample size. Lastly, the qualitative feedback from parents regarding their favourite portions of the DMT group/ their experience with the group was explored with thematic analysis to more fully understand the parent's experiences and felt benefits of the group. The one response that was in French was first translated into English. Then, all of the responses for each question were first coded by participant to see what emerged from the data, such as the mention of what they found particularly beneficial (e.g. words like "community", "playfulness"). Subsequently, based on these codes, we considered which themes emerged most frequently, based on the following definition of a *theme*: "a theme captures something important about the data that represents some level of a patterned response" (V. Braun & Clarke, 2006). We considered a theme to be present if at least 3 of the 5 participants had language coded for that theme.

Results

Descriptive Statistics

Demographics.

The demographic make-up of participants is shared in Table 1b.

Table 1b*Demographic makeup of participants Study 2*

	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5	Overall <i>M(SD)</i>
Age	42	50	48	45	54	47.8(4.60)
Gender	F	F	M	F	F	-
Child Age	8	8	8	25	16	13(7.55)
Child Age at Diagnosis	5	3	3	20	3	6.9(7.36)
Child Gender	M	M	M	F	F	-
Relationship Status	Common- Law	Married	Married	Single	Common- Law	6.60(.762)
Relationship Length	18 yrs.	17 yrs.	17yrs.	N/A	19 yrs.	17.75(.957)
# other children	1	0	0	0	0	-

Note. Parents # 2 and 3 are married to one another, and thus are reporting on the same child

Interpersonal, Dance, and Outcome Variables. Means and Standard deviations of all measures are in Table 2b.

Table 2b

Mean Levels of Key Study Variables by Participant, and Overall Means and SD

	Scale	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5	Overall
		<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M(SD)</i>
Autism Severity	0-2	.67	1.00	.54	1.29	.29	.758(.392)
Communal Strength	0-10	7.50	8.10	7.40	10.00	10.00	8.60(1.30)
Self-Expansion	1-7	6.17	7.00	6.83	6.67	7.00	6.73(.346)
Satisfaction w Life	1-7	5.80	5.20	5.40	1.60	5.20	4.64(1.71)
Caregiving Burden	1-5	2.48	1.90	2.48	4.00	2.24	2.61(.806)
DMT Positive Affect	1-7	6.75	7.00	5.25	7.00	7.00	6.60(.762)
DMT Negative Affect	1-7	1.33	2.33	1.00	1.00	1.00	1.33(.577)
DMT Self-Expansion	1-7	6.00	5.67	4.67	7.00	7.00	6.06(.983)
DMT Burden Relief	1-7	5.40	6.20	4.20	7.00	7.00	5.96(1.18)

Table 3b*Correlations of Key Variables in Study 2*

Variable	1	2	3	4	5	6	7	8	9
1. Autism Severity	1	.620	.178	-.749	.301	.336	.322	.163	-.120
2. Caregiving Burden	-	1	.450	-.918*	.313	.116	-.537	.495	-.285
3. Dance Self-Expansion	-	-	1	-.545	.931*	.823	-.245	.889*	-.016
4. Satisfaction w Life	-	-	-	1	-.544	-.309	.286	-.662	-.034
5. Dance Burden Relief	-	-	-	-	1	.890*	.049	.891*	.252
6. Dance Positive Affect	-	-	-	-	-	1	.331	.596	-.032
7. Dance Negative Affect	-	-	-	-	-	-	1	-.343	.209
8. Communal Strength	-	-	-	-	-	-	-	1	.360
9. Self-Expansion	-	-	-	-	-	-	-	-	1

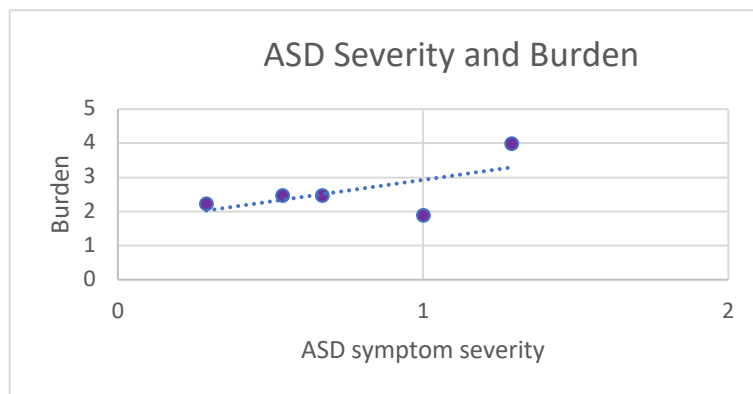
Note: * = $p < .05$

ASD Symptom Severity and Parental Well-being. Our first hypothesis for this sample was that when ASD symptoms were more severe, parents would report more burden, and lower life satisfaction. These parents reported that on average, the severity of their child's ASD symptoms was .67, $SD = .39$. This scale ranges from 0-2, with a 1 representing a problematic behaviour happening "sometimes true over the past 6 months". So, while the mean is not past the midpoint of the scale, it does indicate that the parents in our sample were dealing with a moderate amount of ASD symptoms. It is important to note that one parent's assessment of their child's symptoms was quite a bit higher, with a score of 1.29, and this parent also had the highest burden score, of 4.00 on a scale from 1-5. On average, this sample of parents reported their burden was 2.61, $SD = .80$ which is just over the midpoint of the scale, where 5 represents that

issues related to their child's ASD are “very much so a problem”. Some of the scale items which scored particularly high in this sample were “Feeling tired or strained” with an average score of 3.8, and “feeling worried about the child's future” with an average score of 4.2. So, while this sample of parents does not have extraordinarily high reporting of ASD symptoms, they are still nonetheless experiencing the burdens of caring for a child with ASD. If we consider the relationship between ASD symptom severity, and perceived burden it is a large, positive relationship as we hypothesized, but it is not significant, $r = .620, p = .264$.

Figure 3

Correlation between ASD Severity and Parental Burden



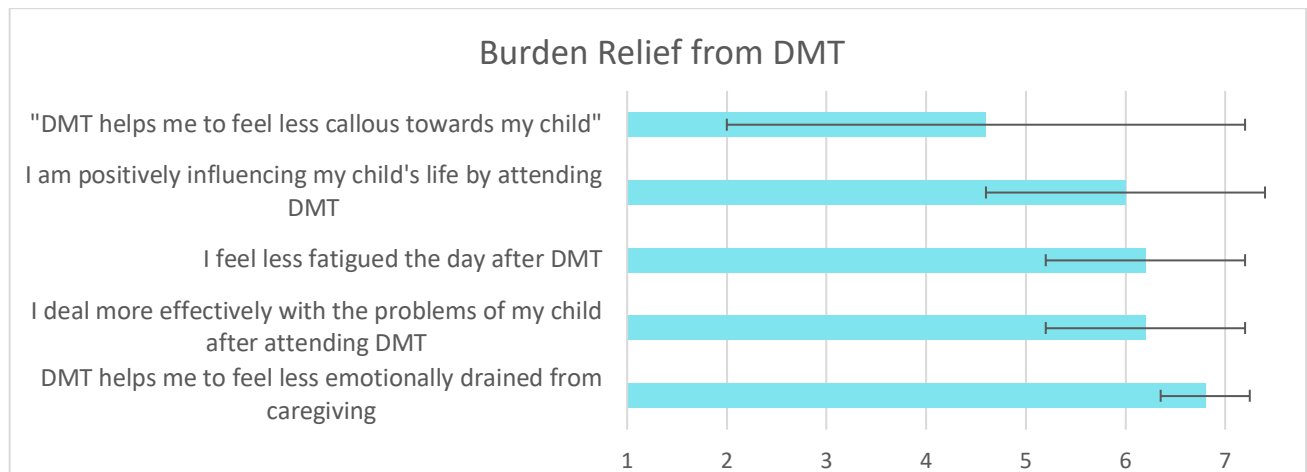
Parents reported that on average, their life satisfaction was $M = 4.64, SD = 1.71$, which is past the midpoint of the 1-7 scale. As hypothesized, life satisfaction was significantly negatively associated with burden severity, $r = -.918, p = .028$, such that the more burden a parent feels, the less satisfied they are with their life. Autism symptom severity was also negatively related to life satisfaction, but not significantly, $r = -.79, p = .145$, indicating that the more severe the ASD symptoms, the less satisfied a parent is with their life.

Interpersonal Variables and Parental Well-Being Outcomes. Second, we hypothesized that when parents reported higher degrees of CS and SE, they would report higher degrees of life satisfaction, and lower degrees of burden (Le & Impett, 2015). This group of parents were all quite high in Communal Strength, with a mean of 8.6 on a 1-10 scale, $SD = 1.30$. This is encouraging, as past research indicates that higher degrees of CS in parents is associated with better mental well-being (Le & Impett, 2015). However, our prediction that higher CS would be associated with lower burden, and higher life satisfaction was not supported in this sample. Higher reports of CS were negatively associated with life satisfaction ($r = -.662, p = .223$) and positively related to burden ($r = .495, p = .397$). Furthermore, this group of parents reported finding their daily life with their child to be highly self-expanding, with an average score of 6.73, $SD = .34$ on a 1-7 scale. This is also an optimistic finding, that these parents are able to find positive, novel consequences of their relationship with their child. This sample of parents seem to find that their child with ASD enables them to “feel a greater sense of awareness of things”, and “learn new things”. While these outcomes are positive, the correlation between SE and burden in this sample was found to be negative ($r = -.285, p = .643$), contrary to our hypothesis. However, when a parent reported more communal strength, this was significantly positively correlated with finding dance more self-expanding ($r = .889, p = .043$), and finding more burden relief from dance ($r = .891, p = .043$), which are both large effects as per (Cohen, 1988) standards, but should be interpreted with caution due to the sample size.

Dance Movement Therapy and Well-Being Outcomes. Third, we expected that the parents would find DMT self-expanding, enjoyable, and report that it helps to reduce their burdens of caregiving. This hypothesis was supported, as parents in this sample found the DMT sessions highly self-expanding, with an average score of 6.06, $SD = .98$ on a 1-7 scale. They also reported on average, that the DMT sessions helped them to relieve perceived burden, with a mean score of 5.96, $SD = 1.18$, on a 1-7 scale where a higher score indicates more burden relief. Considering this scale item by item, one can notice that parents perceived that DMT enabled them to feel less emotionally drained from caregiving ($M=6.8$, $SD= 0.44$), and to deal more effectively with the problems of their child after attending ($M= 6.2$, $SD= 1.00$).

Figure 4

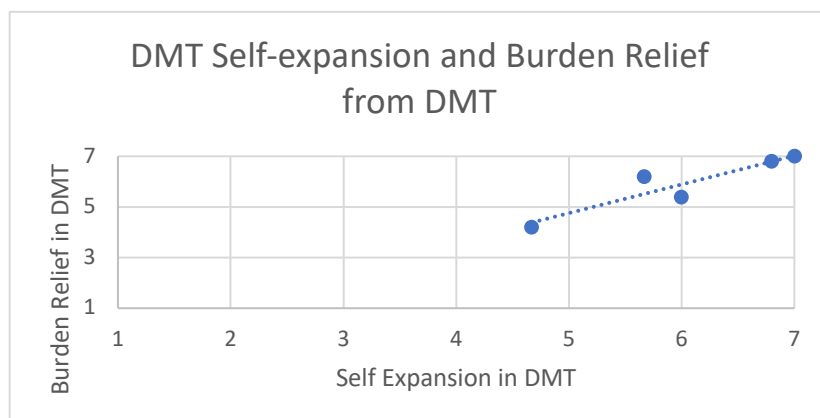
Item means for burden relief from DMT



Furthermore, when parents reported that DMT was highly self-expanding, they also reported experiencing more burden relief from DMT, $r = .931$, $p = .021$, which is a large effect, see Figure 5.

Figure 5

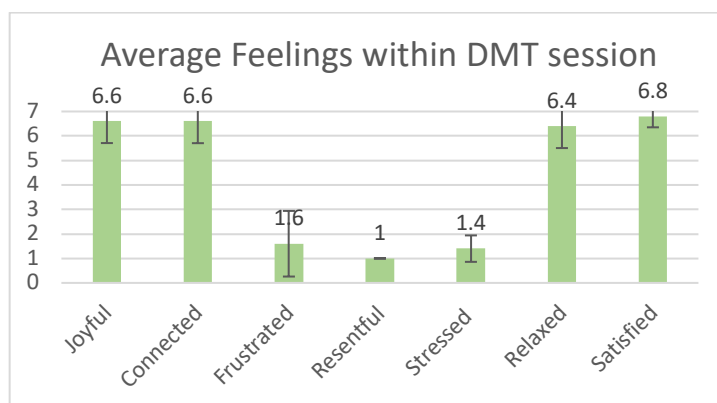
Correlation between self-expansion in DMT and burden relief from DMT



Parents also reported experiencing high levels of positive emotions, and low reports of negative emotions within DMT, as predicted. On average, participants positive affect (combined scores from ratings of connection, joy, relaxation and satisfaction) was 6.60, $SD = .76$ on a 1-7 scale, and when parents reported more positive affect in DMT, they reported significantly more burden relief from DMT, $r = .89$, $p = .043$. Participants also reported experiencing very low degrees of negative affect: $M = 1.33$, $SD = .57$ (frustration, resentment, stress).

Figure 6

Affect within DMT Sessions



In terms of the behavioural measures, parents reported on average that they would recommend friends who have a child with ASD to attend DMT, $M= 4.8$, $SD=.47$, and that they would attend another session of DMT if it was offered, $M=4.8$, $SD=.47$, on a scale from 1 = “strongly disagree”, to 5 = “strongly agree”.

Qualitative Findings

Finally, we reviewed the written feedback from parents based on two open-ended questions in the survey. Parents were asked: “Please describe the parts of the dance therapy session that you find most enjoyable? (describe your favourite components or list the things you enjoy the most)” and “Please share any other comments regarding your personal experience/thoughts on the dance therapy program”. By thematic analysis, we identified three frequent themes of feedback from the parents: 1. Social support, 2. Fun: playfulness, energy and joy, and 3. Mindfulness/ self-awareness. To see every parent’s response to these two questions, see Appendix G.

Social Support. First, four out of the five parents articulated a sense of social support that was elicited within the DMT group and shared the uniqueness of being able to support one another through movement, rather than with words. A father in the DMT group expressed: “When we do exercises with stretchy props (parachutes, elastics) on which we can all pull or lean back as a group in a large circle, I appreciate the strong sense of being “held up” by the rest of the group, and helping to hold it up in turn (physically and emotionally).” Another parent articulated this same idea: “I enjoy finding instinctive meaningful connections with others without a need for any ‘life explanation’”. A mother shared: “I appreciate the sense of community I feel with the other participants, the sense of empathy, understanding and acceptance that comes with shared experiences.” Two of these parents also made specific

mention of their enjoyment of using DMT props that reinforced this feeling of togetherness, such as the Elastablast, or Octaband. These responses are valuable because they indicate that DMT has elicited social support, which we know to be a protective factor for parental caregivers. The parents in this sample seemed to sense that the DMT group was a source of community, and a place to experience “meaningful connection”. This is a promising finding, because past research indicates that perceived social support for parental caregivers of a child with ASD can decrease family burden, and promote parental happiness (Blake et al., 2019).

Fun. Second, three parents indicated that the DMT sessions were fun, which provided them with new energy, life and a sense of spontaneity and/or play. One parent expressed: “I have enjoyed experiencing playfulness and joy again”, and another along the same idea: “The dance therapy program is helping me so much... it is fun!”. One participant even mentioned that her family has noticed a shift in her since she has been attending DMT: “I surprised myself by spontaneously dancing in my kitchen, humming while walking, stretching when experiencing a need for space. My mother mentioned to me that she has noticed a tremendous positive difference in just a few short weeks. *“Life in all its effervescence seems possible again. I am filled with gratitude”*. This feedback goes to show that DMT is a unique opportunity for these parents to experience something fun, new, and that has lasting effects for them, beyond the 1-hour session. This benefit of DMT should not be discounted. These responses also support the reports of DMT being a highly self-expanding activity for these parents.

Mindfulness. Third, three parents expressed a new sense of self-awareness, or mindfulness as a result of DMT. One mother explains: “It is like a moment of permission/encouragement to do something for myself that I need but don't always make time to do... I love that we first translate the feelings into movements, and then think out loud about the

movements that emerge, translating them back into increased self-understanding. This grows layer by layer with each passing class. Mainly it opens to me the possibility to cope better with things because I feel more connected with myself and with my needs, even when it is not possible to meet at the moment my needs, just to be aware of them it is better than before.” Another parent even mentioned how this time to be mindful of their own needs is especially beneficial for them in dealing with their child’s ASD: “After 5 years of a roller coaster ride since we got the diagnosis, the dance therapy class has been like a small oasis of time and space that allowed me to take a break, focus on me a bit.” This theme particularly supports the findings of past research, that interventions for parents of a child with ASD that use mindfulness/ breath work may be beneficial to reduce distress (Da Paz & Wallander, 2017).

Discussion

Parenting a child with ASD is challenging because it can add to parental burden, and lead parental caregivers to be socially isolated (Higgins et al., 2005). Given the immense importance of social support to maintain well-being, investigating interventions that boost perceived social support and coping mechanisms for parental caregivers is essential (Lai & Oei, 2014). In order to build upon previous work, which suggested mindfulness, self-awareness and group interaction to be beneficial for parental caregivers (Da Paz & Wallander, 2017), we considered the experiences of parents who had taken part in a DMT group because of the potential for DMT to foster social support, and reduce distress (Bräuninger, 2012a; Leijssen, 2006) . Indeed, results indicated that on average, parents found DMT to be a highly self-expanding activity and reported that it reduced their burdens of caregiving. As expected, self-expansion in dance and positive affect (connectedness, joy, satisfaction, relaxation) experienced in DMT were significantly associated with more burden relief from DMT, such that the more self-expanding parents felt the DMT

sessions were, and the more connected they felt, the more burden relief they reported experiencing from DMT. While not significant, higher ASD symptom severity was related to more caregiving burden, and lower life-satisfaction (Khanna et al., 2011) as previous research has found. While all caregivers in our sample reported that their child with ASD provided them with many opportunities to self-expand, this was not significantly associated with less caregiver burden. The key themes that emerged from parent's qualitative feedback indicated that DMT was a unique place for them to focus on themselves, become attuned to the present moment through movement and breathwork, have fun, regain energy and also feel a physical and emotional sense of social support, through group movement exercises, the use of DMT props, and times of verbal and embodied sharing with other parents. These themes that emerged from participant's experience are valuable because they highlight that this DMT group was able to elicit known protective factors that past research has suggested to be important for ASD caregivers: social support, and mindfulness.

GENERAL DISCUSSION

Implications and Considerations

In 2018, approximately 1 in 4 Canadians aged 15 and older reported providing informal care for a family member or friend (StatsCan, 2020). While informal caregivers help reduce the burden on formal healthcare systems, and enable those living with various health conditions to stay in their home, caregiving is associated with negative outcomes, such as depression, and burden (Pinquart & Sörensen, 2007). Relationship science literature has indicated that in the general population, self-expanding activities can help to improve relationship satisfaction, and satisfaction with life (A. Aron et al., 2013), and that communal strength is an important interpersonal factor associated with relationship and personal well-being (Le et al., 2018). The

effects of these constructs may be even more important in romantic relationships or parent-child relationships when a loved one faces challenges such as Parkinson's disease or ASD. The literature on what interventions can help caregivers is minimal, but arts-based interventions have been suggested given their potential to foster positive emotions, reduce distress, and also build social support (Fancourt & Finn, 2019). Dance specifically, has been found to strengthen social bonds, open up new ways of moving and thinking, decrease depression and distress, and improve empathy and quality of life (A. Behrends et al., 2016; Bräuninger, 2012b; Meekums et al., 2015).

Given these potential benefits of arts-based interventions for caregivers, we considered how dance-based interventions may benefit the relational and personal well-being of caregivers of a loved one with two different neurological conditions that are on the rise: Parkinson's disease and Autism Spectrum Disorder.

We found that for both types of caregivers (spousal and parental), that the dance activity they participated in was experienced as highly self-expanding. For couples coping with PD, when dance provided more of an opportunity to self-expand with one's partner, this was associated with more positive affect towards one's partner in the dance class. Furthermore, when partners were communally motivated in their participation in the dance class (e.g. felt happy doing something their partner likes in the class), this was associated with greater relationship satisfaction, but care partners did not report that attending Dancing with Parkinson's with their spouse provided much burden relief. For parental caregivers, when they reported that Dance Movement Therapy was more self-expanding, they reported experiencing more burden relief as a result of the DMT sessions. Furthermore, when they experienced more positive emotions within the DMT sessions, and had more communal strength in general, they also reported more burden relief from DMT.

Together, these findings indicate that both adapted dance (DwP), and DMT seem to elicit a high degree of positive emotions (e.g. joy, connectedness), which is suggested to accumulate to a form of “capital” which may buffer against negative experiences (Walsh et al., 2017). These findings add to what we know about arts-based interventions by expanding what is known about the effect of relational variables in Dancing with Parkinson’s: by considering caregiver motivations for attending DwP, and perceived burden relief from these classes. This information is important because it suggests that while DwP may be associated with increased positive emotional capital for care partners, that different interventions without their spouse present may need to be developed, in order to elicit more salient burden relief. Furthermore, the DMT group for parents of a child with ASD was the first of its kind, and while results need to be interpreted with caution, due to the small sample size, do suggest that participants were able to self-expand, gain social support, and find burden relief from caregiving, which are all positive outcomes.

Importantly, two key differences between these samples should be noted. First, for spousal care partners, the individual who they are caregiving for was present in the dance intervention, and for parental caregivers, their child was not present. This is important because as we aim to evaluate interventions for caregivers, the presence of the one they are caring for will certainly impact the types of benefits derived from the activity. While attending DwP together as a couple presented opportunities to be communal, respond to, and self-expand with one’s partner, it is possible that the caregivers who attended were not able to find burden relief because they were still somewhat “on alert” to caring for their partner’s physical and/or cognitive needs within the dance class, and do not feel at ease enough to release their own tension and stress. Therefore, it might be beneficial for care partners to have their own dance class, or DMT group, to give

them the opportunity to experience the benefits of dance, and social support with other caregivers.

Second, while both of the interventions we considered were dance-based, the goals of these two dance activities were very different. Dancing with Parkinson's is by nature, a dance class, learning choreography from a trained dance artist, and focuses on developing dance artistry and technique (DanceforPD, 2017). On the other hand, DMT is facilitated by a trained psychotherapist, and uses movement/dance to work through psychological and emotional themes that emerge from the group's experiences, in order to relieve burdens of caregiving. These differences might also help to explain why the spousal care partners did not seem to derive much burden relief from the dance intervention, because the class is designed for people with PD, not the care partner specifically, as the DMT group was. The pros and cons of these two dance-based interventions should be considered as future interventions for caregivers are designed.

Limitations and Future Directions

A clear limitation of both of the present studies is sample size. Study 1 was a dyadic study, in which it is recommended that 100+ couples are sampled (Kenny et al., 2006). Given that we only had 20 full couples, we are cautious not to generalize the results of our analyses to the wider population. Furthermore, given that we only obtained responses from 12 couples who danced together, and 8 couples where the PwPD danced without their spouse, the comparisons between these two types of couples are less meaningful due to our low power. Moving forward, it will be important to obtain larger sample sizes, so that mechanisms which would help to explain why certain interpersonal variables (e.g. appreciation for one's partner) are associated with greater relational and personal well-being, could be explored for couples coping with a neurological disorder. While some work in the general population has suggested mechanisms for

these associations (e.g. when one is appreciative, they are more responsive to their partner, which results in greater relationship satisfaction (Gordon et al., 2012), investigating these mechanisms further in couples coping with PD would help to provide insight into how couples can best navigate challenges. For example, if we could pinpoint why for the care partners in our sample that self-expansion was associated with less caregiving burden, this would help to inform more effective interventions that reduce care partner burden.

While more dyadic work should be done to further investigate these variables, this will likely not be without sampling challenges. For the present study, it was surprisingly challenging to find couples where the PwPD did not have mobility or cognitive challenges which prevented them from answering the online survey independently (e.g. tremor or lack of muscle control made filling out an online survey difficult). This problem greatly compromised the sample size, as well as the variability of PD symptom severity range that we were able to obtain. Due to the fact that the questions of the survey were relational in nature, we could not have care partners assist their PwPD to answer the survey, as this would introduce too much bias into the responses. Perhaps this is why little research on couples coping with neurodegenerative diseases is dyadic. While these issues greatly limit the generalizability of our results, our sample size is on par with other dyadic research studies carried out on this population, such as (Mavandadi et al., 2014) whose pilot study on benefit finding included 25 dyads, or (Martinez et al., 2018) which had 17 PwPD and 42 care partners recruited to consider empathy and care partner burden. Meta-analyses may be useful order to interpret in the conclusions drawn by the work that exists so far with small samples. Beyond this, in order to yield larger sample sizes, future researchers could obtain data from the partners who have PD through in-person interviews, where the researcher administers the measures, and takes note of their responses. Though this would be more time-

consuming to arrange, it would enable more dyadic data to be acquired for this population of couples.

Sample size also greatly affected our analytic strategy, and generalizability of findings in Study 2. However, given that we were able to obtain responses from 5/7 total participants in the DMT groups, we can be fairly confident that on average, the parents involved in *this* group found it to be beneficial. To be more confident with the reliability of our results, it is important to see if other groups led by a different Dance Movement Therapist, with more participants are able to achieve similar results and findings.

A second limitation of both Study 1 and 2 is that because they were both cross-sectional, we have no way of accounting for changes in personal and/or relational well-being that have occurred over time. For Study 1, given that on average, couples had been attending DwP for three+ years, and dealing with PD diagnosis for 10+ years, it is possible that although depression and burden were quite low in this sample, that they are still an increase from 5 or 10 years prior. It would be ideal for future research to look at a group of couples near the beginning stages of the PD diagnosis, and see how their relationship satisfaction might change over time, through a series of follow up assessments, comparing a group that begins dancing together for the first time, and another group at similar stage of PD that is enrolled in a different arts-based recreation activity (e.g. Singing with Parkinson's). Furthermore, as discussed above, given that the care partners who attended DwP did not experience much burden relief from attending with their partner, in the future it would be interesting to investigate the benefits of dance movement therapy (DMT) for spousal care partners, as this would enable them to move, connect and explore with other care partners, without their PwPD there to take care of.

In Study 2, again, since we only have one snapshot of parents' experience in DMT, it is hard to account for any changes over time. Future research could consider how parents' reports of burden may reduce over the term of DMT, if they were to take pre and post measures of a new group of parents as they begin the same DMT intervention at the beginning and then at the end of the 10-week term. Alternatively, parents could be asked to rate their burden in a daily-diary study, the day before a DMT session, the day of, and the days following, as this would capture a more accurate change in levels of burden, compared to how in the present work we asked parents to retrospectively report burden reduction from DMT.

Lastly, a factor not considered in either Study 1 or 2 was medication. The majority of individuals with PD take L-DOPA, which can help to reduce physical PD symptoms, but also may have specific negative cognitive consequences (Shohamy et al., 2006). If at some point the PwPD begin taking medication for their PD symptoms, it is possible that this could affect degree of symptom severity and/or care partner burden and relationship satisfaction. Therefore, it would be essential to rule medication out as a confounding variable. Similarly, while we were able to account for ASD symptom severity, we did not ask parents if their child was medicated for ASD. This factor must be considered in future research, as the complex relationships between ASD symptoms and parental burden are investigated. It is important that samples of caregivers have a range of participants who care for a loved one with minimal symptoms, to those who care for someone with more extreme symptoms so that the benefit of different interventions can be more fleshed out. For example, what if some interventions are beneficial, only to the extent that one's loved one is well enough, or stable on medication, which enables them to take the time to leave the house to participate in a group activity of their own?

Despite these caveats, this work serves as a preliminary step to considering how dyads cope with PD together, confirming some associations between interpersonal variables (e.g. appreciation, self-expansion) and relationship satisfaction from research on the general population. The present study also suggests that DwP is a meaningful recreational activity for many couples that presents opportunities for communal strength to be expressed, which is associated with being more satisfied in one's relationship. Overall, DwP was rated as highly self-expanding and elicited positive emotions for couples. Furthermore, DMT seems to be a promising intervention for parental caregivers of a child with ASD, based on its multi-dimensional impact, that for our sample was self-expanding, and elicited physical and emotional social support, fun, mindfulness, and burden relief.

Conclusions

Maintaining well-being for informal caregivers is difficult, whether spousal care partners or parental caregivers. Yet, determining which interpersonal factors, and interventions may assist to maintain caregiver health, and relationship satisfaction is of utmost importance, as rates of neurodegenerative conditions such as PD as well as childhood disorders like ASD are on the rise (Christensen et al., 2016). The present research was able to investigate the partner and actor effects of appreciation, communal strength, perceived partner responsiveness, and self-expansion on relationship satisfaction, satisfaction with life and depression, adding to the body of dyadic research for couples coping with PD, and proposing self-expansion as an important buffer of caregiving burden. The relational and personal benefits of Dancing for Parkinson's classes were also considered, and the findings advance what is known about the impact of DwP for care partners. It seems that DwP is a self-expanding activity, which is associated with greater positive emotions towards one's partner, and when partners have more communal strength during dance,

this is related to greater relationship satisfaction. Care partners that attend DwP seem to be motivated to do so for highly communal reasons, and while positive affect in dance is associated with higher relationship satisfaction, they do not report finding it particularly burden relieving. For parents of a child with ASD, the pilot DMT group seems to help them to feel socially supported, to have fun and experience mindfulness, which are all key protective factors for their mental health (Blake et al., 2019; Da Paz & Wallander, 2017), and these findings suggest that more DMT groups for parental caregivers would be beneficial.

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Appendices

Appendix A: Recruitment Poster for Study 1

Do you attend a Dancing with Parkinson's class with your spouse?

WE ARE RECRUITING COUPLES
FOR A RESEARCH STUDY

What will you do?

- A short eligibility email
- Both you and your spouse complete a one-time on line survey
- You will both be entered to win 1 of 4 \$25 dollar gift cards

Who is eligible?

- Couples where both partners are over the age of 50
- One partner is diagnosed with Parkinson's disease
- Couples who have attended at least one term of Dancing with Parkinson's classes

* Other eligibility criteria may apply

email: couplePD@yorku.ca





Appendix B: Example Dancing with Parkinson's Class

Teacher: Robin McPhail-Dempsey, Toronto.

Exercise	Description	Purpose	Music
Name-game introduction	Stating your name with a corresponding, self-generated dance movement. The other dancers first watch, and then repeat back	Welcoming and acknowledging everyone in the class. Practicing skills of projection and choreographing on the spot	N/A

	the participant's name and movement.		
Sun-salutations	Sitting on the chair, using the torso and upper body to scoop down, reach up, feeling resistance in the arms in various patterns. There is an improvised section to pretend to paint the space as if paint were on one's fingers. There is also time for self-directed body tapping/massage where one desires.	Warming up the body, tapping into imagination, creativity and breath.	Instrumental, playful tune.
Upper body warm up	Opening and closing the body, twisting backwards and forewords. Port de bras of the arms, in various ballet positions.	Developing flow of movement, coordination and synchronization of body parts.	Classical music
Lower body work.	Tondues (brushing the foot through the floor to an extension), degages (extension slightly off the floor), grande battement (raising the leg considerably off the ground, with a swooshing motion). Step clap + touch at the chorus of the song.	Developing leg muscles, in seated position. Using force, strength, and musicality in unison with the rhythm of the music.	Ob-La-Di, Ob-La-Da by The Beatles
Waltz- seated version	One-two-three timing, swooshing arm motions, 3 steps of the feet simultaneously. Improvising with the music.	Preparation to do the waltz standing later, developing musicality, balance.	Classic waltz music.
1-minute solo	Dancers have approximately one minute of a song to improvise move/dance their way to standing. They are encouraged to interact with at least one other person in this movement exploration	Developing movement voice, creativity. Functional movement, to safely transition from sitting to standing in creative ways.	Instrumental Pop Music
Plies and port de bras in standing	Holding on to the back of a chair, plie's (bending of the knees) and rises were done in parallel (feet together) and apart. Standing.	Developing strength and balance while standing and increasing range of motion in the legs.	Hey Jude by The Beatles

Waltz in the centre/around the room	Waltz step standing and travelling around the room. Couples are dancing together, and single individuals are with other dancers, or dance volunteers. Dancers are also encouraged to try an “arabesque” which is a one-leg balance,	Social interaction with partner/other dancers, safely navigating dancing through the space, strengthening the legs and core by lunging off balance and returning to a central position.	Classic Waltz Music.
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Appendix C: All Survey Questions for Study 1

General Survey Questions that every participant filled out (whether they attend dance class with their partner or not)

Demographics/ Background Questions

Your age:

Your date of birth (MM/DD/YYYY):

Do you identify as

- Male
- Female
- Other/Not listed. Specify below if you like:

What is your relationship status?

- Married
- Common-law
- Living together
- Living apart
- Other/ Not listed. Specify below if you like:

Duration of relationship: how many years have you been with your current partner? Please count from the start of your relationship, so for example if you have been married for 5 years and 3 months but dated for 3 years and 6 months before then you would list 8 years and 9 months.

____ Years ____ Months

****PD Partner fills out****

At what age were you diagnosed with Parkinson’s disease?

UPDRS Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL) ***PD Partner fills out***

Please response with the most appropriate answer based on how you have felt in the **past week**
Please use the following response to guide your answers:

1.7 Sleep Problems: *Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning.*

0: Normal: No problems.

1: Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep.

2: Mild: Sleep problems usually cause some difficulties getting a full night of sleep.

3: Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night.

4: Severe: I usually do not sleep for most of the night.

1.8 Daytime Sleepiness: *Over the past week, have you had trouble staying awake during the daytime?*

0: Normal: No daytime sleepiness.

1: Slight: Daytime sleepiness occurs but I can resist and I stay awake.

2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.

3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people.

4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.

1.9 Pain and Other Sensations: *Over the past week, have you had uncomfortable feelings in your body like pain, aches tingling or cramps?*

0: Normal: No uncomfortable feelings.

1: Slight: I have these feelings. However, I can do things and be with other people without difficulty.

2: Mild: These feelings cause some problems when I do things or am with other people.

3: Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.

4: Severe: These feelings stop me from doing things or being with other people.

1.10 Urinary Problems: *Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?*

0: Normal: No urine control problems.

1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.

2: Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents.

3: Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents.

4: Severe: I cannot control my urine and use a protective garment or have a bladder tube.

1.11 Constipation Problems: *Over the past week have you had constipation troubles that cause you difficulty moving your bowels?*

0: Normal: No constipation.

1: Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable.

2: Mild: Constipation causes me to have some troubles doing things or being comfortable.

3: Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything.

4: Severe: I usually need physical help from someone else to empty my bowels.

1.12 Lightheadedness and Standing: *Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down?*

0: Normal: No dizzy or foggy feelings.

1: Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.

2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.

3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.

4: Severe: Dizzy or foggy feelings cause me to fall or faint.

1.13 Fatigue: *Over the past week, have you usually felt fatigued? This feeling is **not** part of being sleepy or sad*

0: Normal: No fatigue.

1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people.

2: Mild: Fatigue causes me some troubles doing things or being with people.

3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.

4: Severe: Fatigue stops me from doing things or being with people.

UPDRS Part II: Motor Aspects of Experiences of Daily Living (M-EDL) ***PD Partner fills out***

2.1 Speech: *Over the past week, have you had problems with your speech?*

0: Normal: Not at all (no problems).

1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.

2: Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday.

3: Moderate: My speech is unclear enough that others ask me to repeat myself everyday even though most of my speech is understood.

4: Severe: Most or all of my speech cannot be understood.

2.2 Saliva and Drooling: Over the past week, have you usually had too much saliva during when you are awake or when you sleep?

0: Normal: Not at all (no problems).

1: Slight: I have too much saliva, but do not drool.

2: Mild: I have some drooling during sleep, but none when I am awake.

3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.

4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.

2.3 Chewing and Swallowing: Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?

0: Normal: No problems.

1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.

2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.

3: Moderate: I choked at least once in the past week.

4: Severe: Because of chewing and swallowing problems, I need a feeding tube

2.4 Eating Tasks: Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knives, spoons, chopsticks?

0: Normal: Not at all (No problems).

1: Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating.

2: Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.

3: Moderate: I need help with many eating tasks but can manage some alone.

4: Severe: I need help for most or all eating tasks.

2.5 Dressing: Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow but I do not need help.
- 2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).
- 3: Moderate: I need help for many dressing tasks.
- 4: Severe: I need help for most or all dressing tasks.

2.6 Hygiene: *Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene?*

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow but I do not need any help.
- 2: Mild: I need someone else to help me with some hygiene tasks.
- 3: Moderate: I need help for many hygiene tasks.
- 4: Severe: I need help for most or all of my hygiene tasks.

2.7 Handwriting: *Over the past week, have people usually had trouble reading your handwriting?*

- 0: Normal: Not at all (no problems).
- 1: Slight: My writing is slow, clumsy or uneven, but all words are clear.
- 2: Mild: Some words are unclear and difficult to read.
- 3: Moderate: Many words are unclear and difficult to read.
- 4: Severe: Most or all words cannot be read.

2.8 Doing Hobbies and Other Activities: *Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?*

- 0: Normal: Not at all (no problems).
- 1: Slight: I am a bit slow but do these activities easily.
- 2: Mild: I have some difficulty doing these activities.
- 3: Moderate: I have major problems doing these activities, but still do most.
- 4: Severe: I am unable to do most or all of these activities.

2.9 Turning in Bed: *Over the past week, do you usually have trouble turning over in bed?*

- 0: Normal: Not at all (no problems).
- 1: Slight: I have a bit of trouble turning, but I do not need any help.
- 2: Mild: I have a lot of trouble turning and need occasional help from someone else.
- 3: Moderate: To turn over I often need help from someone else.
- 4: Severe: I am unable to turn over without help from someone else.

2.10 Tremor: *Over the past week, have you usually had shaking or tremor?*

- 0: Normal: Not at all. I have no shaking or tremor.
- 1: Slight: Shaking or tremor occurs but does not cause problems with any activities.

2: Mild: Shaking or tremor causes problems with only a few activities.
3: Moderate: Shaking or tremor causes problems with many of my daily activities.
4: Severe: Shaking or tremor causes problems with most or all activities.
2.11 Getting out of bed, a car, or a deep chair: *Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?*

0: Normal: Not at all (no problems).
1: Slight: I am slow or awkward, but I usually can do it on my first try.
2: Mild: I need more than one try to get up or need occasional help.
3: Moderate: I sometimes need help to get up, but most times I can still do it on my own.
4: Severe: I need help most or all of the time.

2.12 Walking and Balance: *Over the past week, have you usually had problems with balance and walking?*

0: Normal: Not at all (no problems).
1: Slight: I am slightly slow or may drag a leg. I never use a walking aid.
2: Mild: I occasionally use a walking aid, but I do not need any help from another person.
3: Moderate: I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person.
4: Severe: I usually use the support of another persons to walk safely without falling.

2.13 Freezing: *Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor.*

0: Normal: Not at all (no problems).
1: Slight: I briefly freeze but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing.
2: Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing.
3: Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help.
4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.

General Dance Background Questions

How long have you been attending the dance classes for Parkinson's disease?
__ Years __ Months

Which location(s) do you attend dance classes for Parkinson's Disease classes at? Please list all the locations that you attend and the programs name (e.g. Dancing with Parkinson's, Dancing for PD). If you attend multiple locations, indicate which day(s) you attend specific locations

How often do you attend Dancing with Parkinson's? (Circle/select the one that applies)

More than once a week
Once a week
A few times a month
Once a month
Less than once a month

What particular parts of the dance class do you find most enjoyable? (e.g. partnered activities, improvisation, warm-up, across the floor, standing portion)

****Only PD partner fills this out****

Do you take part in any other social/recreational classes/programs designed for Parkinson's disease individually (e.g. Singing with Parkinson's)?

Yes/No

If yes, please list below:

Do you take part in any other social/recreational classes/programs with your partner?

Yes/No

If yes, please list below:

General Individual Difference Measures

Both members of every couple (PD and Caregiver) fill this out

Measure	Authors	Instructions to Participants	Questions
Perceived Partner Responsiveness	Reis (2003)	1 = not at all 5 = very much	<ol style="list-style-type: none"> 1. My partner understands me 2. My partner makes me feel like he/she values my abilities and opinions 3. My partner makes me feel cared for
Communal Strength	(Mills, Clark, Ford, Johnson, 2004). <i>** items 5,7 and 10 are reverse scored.</i>	Keeping in mind your partner, answer the following questions. Circle one answer for each question on the scale from 0 = not at all to 10 = extremely before going on to the next question. Your answers will remain confidential.	<ol style="list-style-type: none"> 1. How far would you be willing to go to visit _____? 2. How happy do you feel when doing something that helps _____? 3. How large a benefit would you be likely to give _____? 4. How large a cost would you incur to meet a need of _____? 5. How readily can you put the needs of _____ out of your thoughts? 6. How high a priority for you is meeting the needs of _____? 7. How reluctant would you be to sacrifice for _____?

			<p>8. How much would you be willing to give up to benefit _____?</p> <p>9. How far would you go out of your way to do something for _____?</p> <p>10. How easily could you accept not helping _____?</p>
Self-expansion Questionnaire	(Lewandowski & Aron, 2002)	<i>INSTRUCTIONS:</i> Answer each question according to the way you feel, using the following scale. Answers range from (1) not very much to (7) very much.	<p>1. How much does being with your partner result in you having new experiences?</p> <p>2. Do you feel a greater awareness of things because of your partner?</p> <p>3. How much does being with your partner expand your sense of the kind of person you are?</p> <p>4. How much does your partner provide you with a source of excitement?</p> <p>5. How much do you feel you gained a larger perspective of things because of your partner?</p> <p>6. How much has being with your partner resulted in your learning new things?</p>

General Outcome-measures of interest

Both members of every couple (PD and Caregiver) fill this out

Measures	Authors	Instructions to Participants	Questions
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Appreciation in Relationships Scale	Gordon et al., 2012	Likert scale	<p>Appreciative subscale</p> <ol style="list-style-type: none"> 1. I tell my partner often than s/he is the best. 2. I appreciate my partner
Couples Satisfaction Index (16-item)	Funk and Rogge (2007)	Each set of items is scaled differently, see each section.	<p>Subscale 1. Please indicate the degree of happiness, all things considered, of your relationship.</p> <p>Extremely Unhappy (0) Fairly Unhappy (1) A little unhappy (2) Happy (3) Very Happy (4) Extremely Happy (5) Perfect (6)</p> <p>Subscale 2. In general, how often do you think that things between you and your partner are going well? (All of the time = 5, Never = 0)</p> <p>3. Our relationship is strong</p> <p>4. My relationship with my partner makes me happy</p> <p>5. I have a warm and comfortable relationship with my partner</p> <p>6. I really feel like part of a team with my partner</p> <p>(Not true at all = 0, Completely true = 5)</p>

			<p>7. How rewarding is your relationship with your partner?</p> <p>8. How well does your partner meet your needs?</p> <p>9. To what extent has your relationship met your expectations?</p> <p>10. In general, how satisfied are you with your relationship?</p> <p>(Not at all = 0, Completely = 5</p>
Geriatric Depression Scale (Short Form)	Yesavage JA, Brink TL, Rose TL, et al.	Choose the best answer for how you have felt over the past week	<p>1. Are you basically satisfied with your life? YES / NO</p> <p>2. Have you dropped many of your activities and interests? YES / NO</p> <p>3. Do you feel that your life is empty? YES / NO</p> <p>4. Do you often get bored? YES / NO</p> <p>5. Are you in good spirits most of the time? YES / NO</p> <p>6. Are you afraid that something bad is going to happen to you? YES / NO</p> <p>7. Do you feel happy most of the time? YES / NO</p> <p>8. Do you often feel helpless? YES / NO</p> <p>9. Do you prefer to stay at home, rather than going out and doing new things? YES / NO</p> <p>10. Do you feel you have more problems with memory than most? YES / NO</p>

			11. Do you think it is wonderful to be alive now? YES / NO 12. Do you feel pretty worthless the way you are now? YES / NO 13. Do you feel full of energy? YES / NO 14. Do you feel that your situation is hopeless? YES / NO 15. Do you think that most people are better off than you are? YES / NO
Satisfaction with life scale	Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985).	Using the 1-7 scale, indicate your agreement with each item by placing the appropriate on the line proceeding that item. 1 = strongly disagree 2 = disagree 3= slightly disagree 4 = neither agree nor disagree 5 = slightly agree 6= agree 7 = strongly agree	1. In most ways my life is close to my ideal 2. The conditions of my life are excellent 3. I am satisfied with my life 4. So far I have gotten the important things I want in life 5. If I could live my life over, I would change almost nothing.

Partner Specific Survey Questions that only individuals (PD or Caregiver) who attend DwP with their spouse filled out.

Partner-specific Dance Measures

*** For Caregivers only***

How often do you attend Dancing with Parkinson's with your spouse? (Circle/select the one that applies)

I attend with my spouse more than once a week

I attend with my spouse once a week

I attend with my spouse a few times a month

I attend with my spouse once a month

I attend with my spouse less than once a month

*** For partner with PD only***

How often do you attend Dancing with Parkinson's with your spouse? (Circle/select the one that applies)

My spouse attends with me more than once a week

My spouse attends with me once a week

My spouse attends with me a few times a month

My spouse attends with me once a month

My spouse attends with me less than once a month

Both members of the couple who attend dance class together

On average, how frequently do the following things occur for you and your partner in a typical dance class?

0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4= always

We sit together

0-----1-----2-----3-----4

We do partnered dances together (sitting or standing)

0-----1-----2-----3-----4

We partner with each other for mirroring activities (improvised movement generated by one person (a leader), and the other partner echoes back the leader's movement, and then switch roles)

0-----1-----2-----3-----4

Scale	Citation	Scale prompt and Likert values	Scale items
Responsiveness	Fuchs and Koch (2014)	0-5 Likert scale 0 = applies not at all 5= applies exactly.	1. Through the movement of my partner, I realize how they feel (e.g. joy, tension)

		Please think about the last situation in which you have moved with your partner in the dance class. Indicated to what extent the following statements apply to you.	<ol style="list-style-type: none"> 2. I can recognize how my partner feels through joint movement 3. Through joint movement with my partner, a connectedness arises 4. I can understand what my partner wants to express with movement
Communal Strength- during DwP	Modified from: Mills, Clark, Ford, Johnson, 2004). <i>scored.</i>	Keeping your romantic partner in mind, answer the following questions based on a typical dance class, rate each item from 0 = not at all, to 10 = extremely.	<ol style="list-style-type: none"> 1. How happy do you feel when doing something your partner enjoys in the dance class? 2. How high of a priority is meeting the needs of your partner in the dance class? 3. How much would you be willing to give up to benefit your partner in the dance class?
Communal Strength Scale- CP motivations to attend DwP	Modified from: Mills, Clark, Ford, Johnson, 2004). <i>** items 5,7 and 10 are reverse scored.</i>	Keeping in mind the specific person, answer the following questions. As you answer each question, fill in the person's initials in the blank. Circle one answer for each question on the scale from 0 = not at all to 10 = extremely before going on to the next question. Your answers will remain confidential.	<ol style="list-style-type: none"> 4. To what extent do you attend the dance class with your partner because you think the class helps them? 5. To what extent do you attend the dance class with your partner because you think your presence in the class helps them? 6. How large a cost would you incur in order to

			attend the dance class with your partner? 7. How high a priority for you is attending the dance class with your partner?
Self-expansion Questionnaire (modified)		<p><i>INSTRUCTIONS:</i> Answer each question according to the way you personally feel, using the following scale. Please place your answer in the space next to each item.</p> <p>1-7 point scale, 1 = not very much, 7 = very much</p>	<p>1. How much does being with your partner in the dance class result in you having new experiences?</p> <p>2. Do you feel a greater awareness of things because of dancing with your partner in the dance class?</p> <p>3. How much does being with your partner in the dance class expand your sense of the kind of person you are?</p> <p>4. How much does your partner provide you with a source of excitement in the dance class?</p> <p>5. How much do you feel you gained a larger perspective of things because of dancing with your partner?</p> <p>6. How much has dancing with your partner resulted in your learning new things?</p>
Feelings about partner in the dance class		<p>To what extent do you experience the following feelings during or after a <u>typical</u> dance class with your partner?</p> <p>1-7 point scale, 1 = not very much, 7 = very much</p>	<p>Joyful</p> <p>Connected to my partner</p> <p>Frustrated</p> <p>Resentful of my partner</p> <p>Stressed</p>

			Relaxed Satisfied with my relationship with my partner
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Caregiver burden questionnaire *Caregiver only*

Maslach burnout inventory (modified)	Maslach & Leiter (2008)	0-6 point scale 0 = never 1 = a few times a year 2= once a month or less 3= a few times a month 4 = once a week 5= a few times a week 6= every day	<ol style="list-style-type: none"> 1. I deal very effectively with the problems of my partner 2. I feel emotionally drained from caring for my partner 3. I feel fatigued when I get up in the morning 4. I feel I'm positively influencing my partner's life through being with them 5. Over time I've become more callous towards my partner
Burnout Inventory- adapted to be burden relief in DwP	Maslach & Leiter (2008) (Modified)	<p>Please respond to each statement by indicating the extent to which you experience the following after attending a DwP class.</p> <p>0 = not at all 1 = a little 2 = somewhat 3 = very much so</p>	<ol style="list-style-type: none"> 1. Attending the dance program helps me to feel less emotionally drained from caring for my partner 2. I deal more effectively with the problems of my partner after attending dance class 3. I feel less fatigued when I wake up in the morning after dance class 4. I feel I'm positively influencing my partner's life through being with them in dance class

Dance measures ***Partner with PD who attends DwP without their spouse only***

Responsiveness in Movement	Fuchs and Koch Embodied Intersubjectivity Scale (2014)	<p>0-5 Likert scale 0 = applies not at all 5= applies exactly.</p> <p>For these next set of questions please consider how you feel when dancing with other members in the class on average, in activities such as partnered dance or mirroring.</p> <p>Please think about the last situation in which you have moved with a dance partner in the dance class. Indicated to what extent the following statements apply to you.</p>	<p>1. Through the movement of my dance partner, I realize how they feel (e.g. joy, tension)</p> <p>2. I can recognize how my dance partner feels through joint movement</p> <p>3. Through joint movement with my dance partner, a connectedness arises</p> <p>4. I can understand what my dance partner wants to express with movement</p>
Self-expansion Questionnaire (modified)		<p><i>INSTRUCTIONS:</i> Answer each question according to the way you personally feel, using the following scale. Please place your answer in the space next to each item.</p> <p>1-7 point scale, 1 = not very much, 7 = very much</p>	<p>1. How much does attending the dance class result in you having new experiences?</p> <p>2. Do you feel a greater awareness of things because of attending the dance class?</p> <p>3. How much does attending the dance class expand your sense of the kind of person you are?</p> <p>4. How much does the dance class provide you with a source of excitement?</p> <p>5. How much do you feel you gained a larger perspective of things because of participating in the weekly dance classes ?</p> <p>6. How much has attending weekly dance classes resulted in you learning new things?</p>

Feelings about self in the dance class		<p>To what extent do you experience the following feelings during or after a <u>typical</u> dance class?</p> <p>1-7 point scale, 1 = not very much, 7 = very much</p>	<p>Happy/pleased/joyful</p> <p>Connected</p> <p>Frustrated</p> <p>Resentful</p> <p>Stressed</p> <p>Relaxed</p> <p>Satisfied</p>

Appendix D: Couples Coping with PD Qualitative Responses and Analysis

Type of Partner	Response to: "Please let us know any additional comments or thoughts on the survey you have"	Theme
PWPD	A survey of couples intimacy that excludes sex???	
PWPD	Contentment can also be affected by financial worries, quite apart from romantic feelings. The survey leaves this factor out.	Complex factors to consider.
Care Partner	I feel that it is good that you have this survey as it helped me to realize how happy we are with each other and that through dance it makes us closer. I have danced since the age of 2 and I am so happy that we as a couple can make a difference with the dancing with Parkinson's program. Thank you for taking such an interest in the disease	Dance and well-being: relational.
Care Partner	A couple of things made it hard to fill out: (a) we happen to be in a transition time now as a couple, so it's really not a 'static' moment to capture a snapshot of my experience of our coupledness. (b) My own emotional and spiritual approach to our relationship makes some of the survey questions feel like nonsequiturs -- particularly around expectations, satisfaction and "helping" or "helplessness." Some of the questions depended on built-in assumptions that I actually *experience* differently. Nonetheless, it's a neat project and I wish you luck with the research!!	Complex factors to consider.
Care Partner	Dance for PD is the happiest part of our week	Dance and well-being: emotional health
Care Partner	Dance for PD is more than a dance program. I have benefitted by attending class and making new friends. I have been accepted by my fellow dancers and have gained much from the social aspect of dance.	Dance and well-being: social health
Care Partner	At times I was confused if I should answer the questions looking at our whole life together or our life since PD entered our space! Naturally our life has changed, especially since dementia is part of our PD journey. As the full time caregiver, I am sure I am looking at life through different lenses than my partner	Complex factors to consider.
Care Partner	One important point that is missing in this survey is the social aspect of the various dance w. PD groups. Also, a point that has been overlooked, is that, as the caregiver I hand over my partner to the volunteers, giving me "time off" to concentrate on the dancing myself without	Complex factors to consider.

	having to care for my partner, while my partner socializes with the volunteers. This is one of the times I don't have to worry/be concerned as the caregiver! Same goes for the social hour; we never sit together. This has been our habit throughout our professional life, our way to meet other people; the 2 of us could talk about it later. Perhaps a more European attitude, whereas North American couples are "glued together"!	
Care Partner	I attend approximately 25% of the dance classes with my spouse but the survey does not allow for more than a yes/no answer. Many care partners I know are occasional dance participants like myself. Including a scale on this question would yield valuable data for the study. Although I attend only occasionally, it is enough to make me feel I am a part of the Dance for PD community and has made me a strong supporter of the programs. Thank you for your efforts in shedding more light on living with PD.	

Appendix E: Example DMT session for Parental Caregivers

Dance Movement Therapist: Andrea de Almeida

Exercise	Description	Purpose	Music
Warm-up	Participants facing each other in a circle, sitting on yoga mats in the centre of the studio. The warm-up is mostly led by the DMT movements are up for interpretation. Movement begins with focusing on one's breath and bringing awareness to one's body and surroundings. light body movements such as turning of the head side to side, and some stretches of the arms is then added. Reaching up and over and side to side, opening and closing the body lying down on the back. This portion ends with rocking back and forth in a little ball.	Giving PC an opportunity to be present, relax the breath and bring their attention to their bodies. To release stress/pain, and to loosen up the body and any tightness/stress being held in the body.	Classical, quiet piano music. French jazz music with a horn in the background.
Locomoting in the space	Individual exploration navigating the dance space.	Developing a theme to explore	Classical music

	Feeling the weight of different parts of the body, twisting, swinging, heavy and lightness. Trying to balance with parts of the body. Coming together and retreating away as a group.	as a group, heaviness and lightness.	
Co-choreography	Each participant offers one movement to describe how they feel at the time. The group mirrors back each participant's movement. The group also embodies the opposite of each movement (e.g. taking the body back, and then falling forewords). As a group, they pick 3 movements.	Time devoted to personal expression, collaborative creation and unity. Empathizing with each PC's movement.	Classical music.
Mirrored Movement	Participants face each other in a circle, each person is aware of others, and they may take turns guiding the movement, with everyone else following the intention or shape of their movement.	To foster social connection, group awareness and empathy. To be seen, and to see others.	Folk music, light and springy
Locomoting with the choreography	Using the three movements the group created before, one at a time, each participant goes across the room on the diagonal, stopping at 3 points to embody the choreographed movements. They are encouraged to use the choreography as a frame, and to adapt it to how they are feeling.	To give a time for personal exploration, creativity, to foster a sense of ownership	Dancer's choice, can choose what song they'd like to perform to.
Discussion + Embodiment of discussion/reflection.	Participants stand or sit in a circle and open-forum style discuss the challenges and high points of their week with their child /what is to come. Other participants may provide feedback, offer suggestions for how to embody these challenges, and express these emotions in	Fostering social support, connection, practical help and suggestions from one another.	N/A

	movement. They may also share how they have successfully used movement with their child/ for themselves in the past week to find grounding		
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Appendix F: All Survey Questions for Study 2

Measure Name and Authors	Measure items
Demographic Questions	<ol style="list-style-type: none"> 1. Are you a parent of a child with ASD? 2. How old are you? 3. How old is your child? 4. Does your child identify as: male, female, other? 5. At what age was your child diagnosed with ASD? 6. Does your child attend the DMT sessions offered at Les Grands Ballets? 7. Do you identify as: male, female, other. 8. What is your relationship status? Married, common-law, divorced, single, widowed, living apart, living together, other. 9. How many years have you been with your current partner? 10. How many other children do you have? 11. Do any of your other children have developmental disorders? If so, which disorders?
Developmental Behavioural Checklist short form (Taffe et al., 2007)	<p>Instructions to participants: Below is a list of items that describe children and youth. For each item that describes your child now or within the past 6 months, please circle 2 if the item is very true, or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Answer all items as well as you can, even if some do not seem to apply to your child.</p> <ol style="list-style-type: none"> 1. Becomes overexcited 0 1 2 2. Chews or mouths objects or body parts 0 1 2 3. Confuses the use of pronouns (e.g. uses <i>you</i> instead of I) 0 1 2 4. Doesn't show affection 0 1 2 5. Grinds teeth 0 1 2

	<p>6. Has nightmares, night terrors, or walks in sleep 0 1 2</p> <p>7. Impatient 0 1 2</p> <p>8. Inappropriate sexual activity with another 0 1 2</p> <p>9. Jealous 0 1 2</p> <p>10. Kicks, hits others 0 1 2</p> <p>11. Laughs or giggles for no obvious reason 0 1 2</p> <p>12. Preoccupied with only one or two particular interests 0 1 2</p> <p>13. Refuses to go to school, activity centre, or workplace 0 1 2</p> <p>14. Repeats the same word or phrase over and over 0 1 2</p> <p>15. Smells, tastes, or licks objects 0 1 2</p> <p>16. Switches lights on and off, pours water over and over, or similar repetitive behaviour 0 1 2</p> <p>17. Stubborn, disobedient, or uncooperative 0 1 2</p> <p>18. Says he/she can do things he/she is not capable of 0 1 2</p> <p>19. Sees, hears, something that isn't there, hallucinations 0 1 2</p> <p>20. Tells lies 0 1 2</p> <p>21. Tense, anxious, worried 0 1 2</p> <p>22. Underreacts to pain 0 1 2</p> <p>23. Upset or distressed over small changes in routine or environment 0 1 2</p> <p>24. Wanders aimlessly 0 1 2</p>
Communal Strength Scale (General) (Mills, Clark, Ford & Johnson, 2004)	<p>Instructions to Participants: Keeping your child with ASD in mind, answer the following questions. Please rate each item from 0 (Not at all) to 10 (Extremely).</p>

	<p>1. How far would you be willing to go to visit _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>2. How happy do you feel when doing something that helps _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>3. How large a benefit would you be likely to give _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>4. How large a cost would you incur to meet a need of _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>5. How readily can you put the needs of _____ out of your thoughts? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>6. How high a priority for you is meeting the needs of _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>7. How reluctant would you be to sacrifice for _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>8. How much would you be willing to give up to benefit _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>9. How far would you go out of your way to do something for _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p> <p>10. How easily could you accept not helping _____? 0 (extremely) 1 2 3 4 5 6 7 8 9 10 (extremely)</p>
Self-expansion questionnaire (general) (Lewandowski & Aron, 2002)	<p>Instructions to participants: Answer each question according to the way you feel, using the following scale. Answers range from (1) not very much, to (7) very much.</p> <p>1. How much does being the parent of your child result in you having new experiences? 1 (not very much) 2 3 4 5 6 7 (very much)</p>

	<p>2. Do you feel a greater awareness of things because of your child? 1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>3. How much does being with your child expand your sense of the kind of person you are? 1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>4. How much does your child provide you with a source of excitement? 1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>5. How much do you feel you gained a larger perspective of things because of your child? 1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>6. How much has being with your child resulted in your learning new things? 1 (not very much) 2 3 4 5 6 7 (very much)</p>
Satisfaction with life scale (Diener, Emmons, Larsen & Griffin, 1985)	<p>Instructions to participants: Using the 1-7 scale, please indicate your agreement with each item by placing the appropriate on the line proceeding that item. 1 = strongly disagree 2 = disagree 3= slightly disagree 4 = neither agree nor disagree 5 = slightly agree 6= agree 7 = strongly agree</p> <p>1. In most ways my life is close to my ideal 1 2 3 4 5 6 7</p> <p>2. The conditions of my life are excellent 1 2 3 4 5 6 7</p> <p>3. I am satisfied with my life 1 2 3 4 5 6 7</p> <p>4. So far I have gotten the important things I want in life 1 2 3 4 5 6 7</p> <p>5. If I could live my life over, I would change almost nothing. 1 2 3 4 5 6 7</p>

<p>Caregiver Strain Questionnaire (Brennan & Heflinger, 1997)</p>	<p>Instructions to participants: Using the 1-5 scale, with (1) = not at all, to (5) very much so a problem, please indicate how much of a problem each occurrence or feeling described in the last 6 months as a result of your child</p> <ol style="list-style-type: none"> 1. Interruption of personal time 1 2 3 4 5 2. Missing work or neglecting other duties 1 2 3 4 5 3. Disruption of family routines 1 2 3 4 5 4. Family member having to do without things 1 2 3 4 5 5. Family member suffering mental/physical health effects 1 2 3 4 5 6. Child having trouble with neighbours or law 1 2 3 4 5 7. Financial strain 1 2 3 4 5 8. Less attention paid to any family member 1 2 3 4 5 9. Disruption of family relationships 1 2 3 4 5 10. Disruption of family social activities 1 2 3 4 5 11. Feeling socially isolated 1 2 3 4 5 12. Feeling sad or unhappy 1 2 3 4 5 13. Feeling embarrassed 1 2 3 4 5 14. Relating well to child (reverse scored) 1 2 3 4 5 15. Feeling angry toward the child 1 2 3 4 5 16. Feeling worried about child's future 1 2 3 4 5 17. Feeling worried about family's future 1 2 3 4 5 18. Feeling guilty about child's illness 1 2 3 4 5 19. Feeling resentful toward child 1 2 3 4 5 20. Feeling tired or strained 1 2 3 4 5
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	<p>21. Toll taken on family</p> <p>1 2 3 4 5</p>
Dance class -specific questions about enjoyment	<p>Instructions to participants: please respond to the following questions based on how you feel on average about the dance therapy sessions.</p> <p>1. What particular parts of the dance therapy session do you find most enjoyable?</p> <p>2. How much did you enjoy attending the dance therapy sessions every week? (1) = not at all, (5) = very much so</p> <p>1 2 3 4 5</p> <p>To what extent do you experience the following feelings during or after a typical dance therapy session? With (1) = not very much, to (7) = very much</p> <ul style="list-style-type: none"> • Joyful 1 2 3 4 5 6 7 • Connected 1 2 3 4 5 6 7 • Frustrated 1 2 3 4 5 6 7 • Resentful 1 2 3 4 5 6 7 • Stressed 1 2 3 4 5 6 7 • Relaxed 1 2 3 4 5 6 7 • Satisfied 1 2 3 4 5 6 7
Dance-specific adapted scales from self-expansion (Lewandowski & Aron, 2002) and Maslach burnout inventory	<p>Instructions to participants: Answer each question according to the way you personally feel, using the following scale. Please place your answer in the space next to each item.</p> <p>1-7-point scale, 1 = not very much, 7 = very much</p> <p><u>Burnout Inventory (adapted to be dance specific)</u></p> <p>1. Does attending the dance program help you to recover from feeling emotionally drained from caring for your child? If so, how much?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p>

	<p>2. I deal more effectively with the problems of my child after attending a dance therapy session</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>3. I feel less fatigued when I wake up in the morning after attending a dance therapy session the previous day</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>4. I feel I'm positively influencing my child's life through attending dance therapy</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>5. Does attending a dance therapy session help you to feel less callous towards your child?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p><u>Self-expansion (adapted to be dance specific)</u></p> <p>1. How much does being in the dance therapy group with other caregivers result in you having new experiences?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>2. Do you feel a greater awareness of things because of dancing with other caregivers in the dance therapy sessions?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>3. How much does being with other caregivers in the dance therapy session expand your sense of the kind of person you are?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>4. How much does being with other caregivers provide you with a source of energy?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p> <p>5. How much do you feel you gained a larger perspective of things because of dancing with other caregivers?</p>
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	<p>6. How much has dancing with other caregivers resulted in your learning new things?</p> <p>1 (not very much) 2 3 4 5 6 7 (very much)</p>
Dance behavioural measures	<p>1. I would recommend that friends in my situation (caring for a child with ASD) should attend a dance therapy class like this. (1) = strongly disagree, to (5) strongly agree</p> <p>1 2 3 4 5</p> <p>2. I would attend another session of this dance program if it were offered (1) = strongly disagree, to (5) strongly agree.</p> <p>1 2 3 4 5</p>

Appendix G: ASD Parental Caregivers Qualitative Responses and Analysis

Caregiver	Q1. Please describe the parts of the dance therapy session that you find most enjoyable? (describe your favourite components, or list the things you enjoy the most)	Themes- Q1
P1	<p>The stretching component feels both beneficial and very accessible even from the very first sessions of the course. It is like a moment of permission/encouragement to do something for myself that I need but don't always make time to do.</p> <p>Naming emotions and attempting to express them through gesture and movement was the most challenging part of the earliest classes, feeling unfamiliar and coming with a bit of anxiety, of wanting to "get it right" but not yet feeling quite sure how. But after a full session, that is the part that I am appreciating the most. It has become more intuitive with time, more free, and it slowly but surely leads to helpful insights. I love that we first translate the feelings into movements, and then think out loud about the movements that emerge, translating them back into increased self-understanding. This grows layer by layer with each passing class.</p>	<ul style="list-style-type: none"> • Self-awareness/ mindful of one's needs • Social support

	When we do exercises with stretchy props (parachutes, elastics) on which we can all pull or lean back as a group in a large circle, I appreciate the strong sense of being "held up" by the rest of the group, and helping to hold it up in turn (physically and emotionally).	
P2	I appreciate the sense of community I feel with the other participants, the sense of empathy, understanding and acceptance that comes with shared experiences.	<ul style="list-style-type: none"> • Social support
P3	Group activities like everybody pulling from the same strings or rotating ensemble	<ul style="list-style-type: none"> • Social support felt in group activities with props
P4	Experiencing playfulness and joy again , finding instinctive meaningful connections with others without a need for any "life explanation" , learning to feel and listen to my body's own inner wisdom, obvious interplay of conscious and subconscious, so much more!	<ul style="list-style-type: none"> • Fun: Playfulness, energy, joy • Social support and connection
P5	The environment of the class, and the professionalism of the services offered.	
Caregiver	Q2. Please share any other comments regarding your personal experience/thoughts on the dance therapy program:	Themes- Q2
P1	<p>One of the best parts of the therapy is the fact that it is offered in the same time and location as my son's dance therapy, so we have already invested the effort of getting out the door. Given how much other therapy we have to do, that is huge. I also don't need to think about whether someone is available to be with my son while I do my dance therapy.</p> <p>If my son were planning to continue his program, I would answer 5 to the last question without hesitating. However, he now feels ready to move on and do some other things in that time slot. I am still highly tempted to return to the therapy by myself, as I feel I have something to gain from staying in the group longer, but if he is not there at the same time it becomes an "extra" thing for us to organize as a family, so more "costly" in terms of time and organization than it has been this session. That is the only reason I answered 4 instead of 5.</p>	<ul style="list-style-type: none"> • Practical ease
P2	The dance therapy program is helping me so much. It is fun and mainly it opens to me the possibility to cope better with things because I feel more connected with myself and with my needs , even when it is not possible to meet at the moment my needs, just to be aware of them it is better than before.	<ul style="list-style-type: none"> • Fun: Playfulness, energy, joy • Self-awareness/mindful of one's needs

P3	After 5 years of a roller coaster ride since we got the diagnosis, the dance therapy class has been like a small oasis of time and space that allowed me to take a break, focus on me a bit , share experiences with other parents in the same journey, and have some fun on top of it.	<ul style="list-style-type: none"> • Self-awareness/mindful of one's needs • Social support • Fun: playfulness, energy joy.
P4	I surprised myself by spontaneously dancing in my kitchen, humming while walking, stretching when experiencing a need for space. My mother mentioned to me that she has noticed a tremendous positive difference in just a few short weeks. "Life in all its effervescence seems possible again. I am filled with gratitude."	<ul style="list-style-type: none"> • Fun: playfulness, energy, joy • Other close family members noticing a change
P5	I am happy when I participate. Thank you!	