

## **Re- Defining ‘Movement’ in ‘Movement Disorders’**

Development of Community Based Therapeutic Dance Program for Parkinson’s Disease based in the Indian Cultural Context.

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### **Introduction**

Parkinsons’ disease (PD) is a degenerative neurologic disease (Weiner et al., 2007). The symptoms of Parkinson’s, which include tremor, rigidity, slowness of movement and loss of postural balance leading to falls, result from loss of dopaminergic neurons in the substantia nigra pars compacta which innervate the striatum (Hallett et.al., 2004). Depression, anxiety, fatigue and sleep disorders occur commonly in patients with PD. These non-motor symptoms often contribute to the reduction of functional abilities in PD patients (Shulman et al., 2002).

Research with PD and dance has been based on dance forms like Tango, Salsa, American Ballroom, Irish Set dancing, Tai Chi and improvisation in areas of physical mobility, participation, non-motor symptoms, disease severity and quality of life (Westbrook and McKibben, 1989; Hackney et al., 2007; Hirsch, 2009; Hackney and Earhart, 2009a,b,c, 2010a,b; Batson, 2010; Heiberger et al., 2011; Li et al., 2012; Brauninger, 2012; de Dreu et al., 2012,2014,2015; Duncan and Earhart, 2012,2014; Foster et al., 2013; McKee and Hackney, 2013; Volpe et al., 2013; Sharp and Hewitt, 2014; Shanahan et al., 2015a,b; Aguiar et al.,2016 ). Importance of music in dancing for people with PD has been vital to observing the positive effects (Krumhansl, 2000; Hayakawa et al., 2000; Laukka, 2006; Keus et al., 2007; Nieuwboer et al., 2007; Zentner et al., 2008; de Bruin et al., 2010; de Dreu et al., 2014; Koelsch, 2014; Stork et al., 2015). Evidence of Dance/Movement Therapy (DMT) as a

complementary treatment has been observed in the works of Westbrook and McKibben (1989) and Bunce (2002, 2006).

The aim for developing the community based therapeutic dance program for PD, was for it to be implemented in the multiple support groups run by The Parkinson's Disease and Movement Disorder Society across the country. The program was designed based on the work done with support groups in Mumbai. At a support group in a multicultural city like Mumbai, the demographics vary widely in terms of gender, age, disease severity, religion, language, caste, class, education and exposure. In a community based design, it is important to understand how the word 'Dance' is perceived, the gender differences where men and women who were not married to each other would neither dance with each other nor in front of others, the instructions and the sharing that followed after had to be translated and interpreted as a community, the difference in their symptoms, the support systems available at home, exposure to movement forms and their willingness to try an unconventional approach. These factors played a vital role in the interventions designed for the program.

This paper aims at describing the community based therapeutic dance program designed for people with PD. It looks at the amalgamation of the techniques of DMT and Indian folk forms to develop an effective complementary practice to the already existing conventional forms of treatment available to people with PD in India. It also includes a brief description of a preliminary study done to evaluate the effectiveness of dance and the further development of the program based on the study. The program has been under continuous development based on the insights and challenges faced within the Indian cultural context.

### **Cultural Consciousness**

Transcending cultures to co- create a safe movement space is vital to the therapeutic process (Boas, 1989). Each culture has its own distinct rituals, folk forms and stories. The program honors differences in the cultural frameworks which enhance ethical therapeutic practice. Initially, the participants engaged in structured and taught movement patterns, which then developed into movement improvisations and were relatively unstructured. The material and movements to be worked with were brought into the space by the participants of the group.

The support groups are a free service provided to people with PD and their caregivers. It is an open group format which created a challenge in establishing boundaries of a psychotherapeutic approach. The program started with familiar and simple forms of movements to familiar music and rhythms. Elements of partnered dances like tango and salsa were simplified to be experienced either alone or with the facilitator due to conservative cultural fabric. Some of the caregivers would involve themselves enthusiastically along with the participants. This opened up channels of communication in movement and verbally between the caregivers and the participants. The participants then progressed to creating individual movements and moving together as a group, leading to reduction in difficulties in movement initiation, tremors and falls. The group process evolved to facilitate inclusion and support new members. This worked towards reducing inhibition regarding the common notion of participants that ‘dancing at the age of 60 – 70 years is unheard of’.

### **Moving Connections**

Bringing in the memories, stories and emotions in movement form helped the participants harness their inner voice in a creative manner. It led to spontaneous sharing, kinesthetic empathy and attuning to the needs of one another. Working with symbolism (Schmais, 1985) and movement metaphors (Meekums, 1996; Halprin, 2002), the participants identified those aspects of PD which had resulted in losing their sense of identity. The program was designed to use visualizations relating to participants’ life experiences and approaching movement using sensory modalities. Mirroring (Chaiklin and Schmais, 1993) paved the way for building meaningful connections with their own selves and bodies. Learning and practicing techniques of grounding was effective in reduction of falls and creation of new movement patterns for support. The program aimed at increasing self awareness, environmental awareness, moving between dependence and independence, consciously attending to the process rather than the product.

### **Kaleidoscopic folk movements**

The program encourages participants to spontaneously combine movement patterns, group formations and rhythms from their own cultural background. The group came up with

innovative movement combinations and permutations in every session. An increase in confidence and active participation to display cultural forms to one another was observed. While the group mirrored most of these movements, witnessing the way the participants responded, a sense of belonging developed. Group formations of circle, concentric circles, moving in dyads and triads are very natural in Indian folk forms. The tribal patterns and use of circles (Hamill et al.,2011) when embedded in the work of Marian Chace (Chaiklin and Schmais,1993) allowed for shared leadership to emerge. Multiple rhythms and familiar music provided an emotional environment, altered dispositions and may have helped in reduction from sensations such as weariness (Laukka ,2006; Zentner et al., 2008; Stork et al., 2015)

### **Story Telling Using Body and Body Memories**

The program provided an opportunity for the participants and their caregivers to express their personal stories and journeys of their navigation of PD. The program was designed to allow for processing of how PD affected the bodies in the present moment. Anecdotally, some of the participants also were able to reconnect, with certain movement patterns of their childhood and shared the disappointment of how permission was given to PD to take over the enjoyable movements.

### **Preliminary study**

This was one of the first studies done within the Indian population that systematically investigated the effects of dance on PD in 2011. The purpose of this study was to evaluate the effect of movement and dance in a Within Group Design: pre-test and post-test with the same group. Twenty two subjects with PD were divided into three groups based on the geographical area of the community centre. Subjects completed a total of 16 sessions and were evaluated a week before and after the intervention. The Berg Balance Scale and The PDQ-39 were administered to evaluate the effectiveness of the intervention. Significant difference found in 6 out of the 8 domains. These domains were mobility, emotional well-being, activities of daily living, stigma, cognition and bodily discomfort. No significant difference was observed on the scores of the pre-test and the post-test on the Berg Balance Scale.

## **Evidence based Practice and Further Development**

It is imperative to make the distinction about the focus of the program being therapeutic dance as opposed to dance therapy. The need of licensed and trained DMTs in India, the support group format, the large numbers of people with PD make it difficult for DMT to be available to masses as a complementary therapy. However, there are smaller closed groups where DMT is being practiced.

The community based therapeutic format is being adapted by other conventional forms of therapy like physiotherapy and speech therapy by The Parkinson's Disease and Movement Disorder Society. The society has developed a multi-disciplinary model for the support groups across the country. Therapeutic dance has found its place in the model as 1 of the 12 sessions offered to the participants through the year. The program continues to develop by incorporation of diverse movement forms, rhythms and techniques borrowed from other expressive art modalities. There is also an element of performance that has been added where there is display of movement on World Parkinson's Day and at other awareness programs.

## **Re-Defining 'Movement' in the 'Movement Disorders'**

There has been a significant increase in the acceptance of therapeutic dance and DMT by medical practitioners, allied health professionals, caregivers and participants as a complementary form of treatment in India. It celebrates the experiences that life has to offer in movement and adds a new connotation to the word movement for people with PD.

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