



Contents lists available at ScienceDirect

Complementary Therapies in Clinical Practice

journal homepage: www.elsevier.com/locate/ctcp

A qualitative examination of physiotherapist led community-based yoga for individuals with Huntington's disease



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ARTICLE INFO

Article history:

Received 18 May 2017

Accepted 6 June 2017

Keywords:

Huntington's disease

Yoga

Qualitative

Exercise

Mindfulness

Physiotherapy

ABSTRACT

Purpose: The purpose of this study is to examine community-based yoga, led by a physiotherapist, for individuals affected by Huntington's disease (HD).

Methods: Qualitative case study methodology was used to examine the Hatha yoga led by a certified yoga instructor who was a neurologic physiotherapist. Data collection included participant observations, semi-structured interviews with the instructor, and structured participant surveys. Data were coded and thematically analyzed. Strategies for rigor included field engagement, triangulation, member checks, and reflexivity.

Outcomes: Five major themes emerged regarding the value and role of yoga for individuals affected by HD: [1] Emphasis on mindfulness, [2] Yoga is modifiable and accessible, [3] Precise communication, [4] Yoga fosters a sense of community, and [5] Poses tailored to HD-specific deficits.

Conclusions: Yoga led by a physiotherapist can be tailored to enable participation by those affected by HD, addresses HD-specific deficits, and promotes a sense of community to supplement traditional physiotherapy.

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1. Introduction

Huntington's disease (HD) is a neurodegenerative disorder caused by an abnormal expansion of Huntingtin gene CAG repeats. Individuals with >35 CAG repeats express HD and the greater the expansion, the earlier the disease onset, with an average onset of 40 years old [26]. HD is characterized by behavioral/psychological changes (e.g., depression, low self-esteem, anxiety), cognitive deficits (e.g., attention deficits, dementia), and movement dysfunction that lead to functional decline and ultimately death within 15–30 years post diagnosis [5,28].

A systematic review in 2003 describes the absence of evidence for the role of physiotherapy for individuals with HD [3]. Since that time, a paradigm shift in HD research has moved the conversation beyond palliative care to an emphasis on examination of rehabilitation interventions that potentially postpone the cognitive and functional deterioration [4]. This shift is similar to work in other neurodegenerative diseases, such as Parkinson's disease (PD),

previously assumed to not be amenable to exercise and rehabilitation to which there is growing refuting evidence [11,13,25].

Like PD research, evidence is emerging that demonstrates rehabilitation interventions positively influence motor and functional performance of individuals with HD [33]. Continued examination of specific exercise approaches to determine optimal interventions for individuals with HD is needed.

Research and clinical reports describe the safety, feasibility, and acceptability of community-based exercise programs for people with HD [5,6]. Clark et al. [6] describes a case series of individuals with or at-risk for HD who demonstrated improvements in balance, gait, and fatigue after an 8-week community-based group exercise program. Integration of yoga was a suggestion offered by the authors to evolve the program.

Yoga can improve balance, flexibility, lower extremity strength, muscle control, cardiopulmonary function, depression, and anxiety [16]. Others have reported positive impacts on attention and body awareness [30]. Yoga is emerging as a modality for neurological populations. The effects of yoga on posture, balance, strength, and functional mobility in individuals with PD are described [10]. A randomized control trial demonstrated that a yoga program for individuals with PD increased muscle strength and power,

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improved self-reported quality of life, was well-received by patients, and had an exceptional level of adherence [23]. Researchers suggested consideration of yoga as viable and valuable to patients with PD to improve functional performance of daily activities [23].

Research is needed that examines the role and value of yoga for those with HD, another neurodegenerative disease rooted in the basal ganglia like PD. There is no work to date that examines the role of a physiotherapist-led yoga class for individuals with HD. The purpose of this study is to examine and describe the qualities of a community-based yoga program led by a physiotherapist for individuals affected by HD using qualitative methods that enable rich, meaningful descriptions.

2. Methods

2.1. Study design

Qualitative case study methodology to explore the program within a bounded system was most appropriate [12]. This case was bounded by setting ([Redacted for blind review] Hospital in [Redacted for blind review]), program (yoga for individuals with HD), and time (two classes). The Institutional Review Board of [Redacted for blind review] approved this study (IRB #[Redacted for blind review]).

2.2. Setting & participants

The pro bono weekly community-based exercise class included strengthening exercise, balance training, music therapy, and yoga for individuals affected by HD. On average, three individuals with HD, one person at-risk for HD, and two caregivers attended each class. The group was normally led by one therapeutic professional accompanied by volunteers for a total of 60 min.

A certified yoga instructor, who was also a licensed physiotherapist who completed a neurological residency credentialed by the [Redacted for blind review], led the Hatha style yoga-specific classes. There were six participants on the first day of observation and five participants on the second day of observation.

2.3. Research team

The research team consisted of two doctor of physiotherapy students in their third and final year of the program and two doctor of physiotherapy program faculty, both of whom were board certified in neurologic physiotherapy by the [Redacted for blind review], taught neurologic coursework in the program, and mentored students at a physiotherapy service learning movement disorders clinic. One faculty researcher had previous experience conducting qualitative studies in neurorehabilitation and led the discussion on qualitative methods and integrating the team's knowledge of HD and yoga to inform the data collection and analysis.

This study reflects “insider research” in which we conducted the study within a program and type of intervention of which we were members [19]. One of the faculty researchers was a co-founder of this community-based group class that began several years prior to this study. Also, two of the researchers regularly participated in yoga. This insider research approach supported easier access and entry to the setting and program [1,9], participants' acceptance of the researchers' presence and role [15], and development of rapport through a shared identity and language [1]. An additional benefit was the richness and depth of the participant observations and subsequent analysis possible given the researchers' lens of previous experiences participating in yoga, working with individuals with HD, and being physiotherapists.

2.4. Data collection

Participant observation is a qualitative technique in which researchers immerse themselves in the environment of interest [12]. Participant observation was selected as the primary data collection approach in order to observe the interactional processes between the instructor and participants and the social aspects of the program [7]. We hypothesized that an understanding of the human behavior and interactions within the program would best illuminate factors that contributed to the success and popularity of the program. Two researchers attended the yoga class and completed in-depth observations with copious field notes [8] regarding the physical space, the instructor's interactions with the group, cues given, flow of the class, the participants, and specific modifications to the yoga poses for the participants.

Prior to observing the yoga classes, the two researchers interviewed the yoga instructor to obtain foundational background information and her perceptions of yoga for individuals with HD. A semi-structured interview guide was provided to the instructor before the interview to enable thoughtful reflection prior to the conversation (Table 1). The interview was also open to spontaneous questions as the conversation developed. The participant observations that followed the interview enabled a direct observation of the instructor's yoga and physiotherapy expertise to the class, observing her words in action.

Following the second class, the 5 participants completed a program satisfaction survey to provide the yoga instructor with feedback (Table 2). The anonymous surveys are presented as a means of sharing the participant's general perceptions of the class.

2.5. Data analysis

We analyzed data from the interview with the yoga instructor, the de-identified participant observations of two consecutive weekly yoga classes, and the participant surveys. The data were transcribed and coded manually for themes. Key determinants that potentially contributed to the optimal design and success of this program were identified.

Strategies to ensure rigor addressed the four criteria of credibility, dependability, confirmability, and transferability [17]. For credibility, prolonged engagement, triangulation of data sources, and member checking were used [17]. While the participant observations with field notes only occurred over two classes, the two researchers who completed the observations volunteered weekly with the HD exercise group for several weeks prior to the observation period. One of the faculty research team members started the exercise class three years prior and had led the group on numerous occasions. This prolonged engagement in the setting enabled a fuller understanding of the program.

Triangulation occurred through an examination of multiple data sources including the instructor interview, participant observations, and participant surveys. The instructor was invited to review the findings and provide feedback as a means of member checking. To address dependability and confirmability, an audit trail of

Table 1

Sample questions from the semi-structured interview guide.

- 1) What are the potential benefits to individuals affected by Huntington's disease (HD) of coming to a yoga class taught by a physiotherapist?
- 2) What are the major barriers and facilitators to leading a yoga class for people with HD?
- 3) Can yoga be adapted as the needs of individuals with HD change over time? If so, how?
- 4) There are several barriers to exercise that lead to decreased adherence and activity levels in the HD population. What role does yoga play in helping individuals overcome the barriers?

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