

# Feasibility and Safety of an Aquatherapy Program in Mid- to Late-Stage Huntington Disease

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## Abstract

**Background:** The progressive motor dysfunction and cognitive impairment associated with mid- to late-stage Huntington Disease (HD) renders few exercise programs amenable for use in this population. Exercise may slow the symptomatic progression of HD, therefore appropriate programs should be available to those with advanced disease. The pool, with a low risk of falling, boasts an appropriate environment to support choreic limbs. The purpose of this qualitative questionnaire-based study was to assess the feasibility and safety of aquatherapy in mid- to late-stage HD, and program perception by participants/caregivers.

**Methods:** Six participants with manifest HD completed a six-week aquatherapy program comprised of twice-weekly sessions. Participant-tailored aquatherapy sessions involved a warm-up, exercise-set, and a cool-down. Study notes regarding injury and compliance were recorded to track measures of safety and feasibility. Participants (and caregivers where available) gave an interview following the program. Conversations were audio recorded and fully transcribed. Interviews were analyzed to extract themes.

**Results:** Generally, participants reported the aquatherapy to be enjoyable, feasible, and safe, as well described improved mood, sleep, and quality of life. Anecdotal evidence suggests that many participants experienced improved physical conditioning.

**Conclusions:** Twice-weekly aquatherapy is feasible in mid- to late-stage HD, and was perceived to be safe and enjoyable.

**Keywords:** Aquatherapy; Hydrotherapy; Huntington disease; Movement disorders

## Introduction

Huntington Disease (HD) is a predominantly adult-onset neurodegenerative disease with autosomal dominant inheritance. HD is caused by a cytosine-adenine-guanine (CAG) trinucleotide repeat expansion mutation in the *huntingtin* (*HTT*) gene on chromosome 4 [1,2]. This CAG repeat expansion encodes for a polyglutamine stretch in the N-terminal of the huntingtin protein resulting in a toxic gain-of-function of the mutant protein and selective neurodegeneration. Certain regions of the central nervous system are preferentially sensitive to mutant huntingtin toxicity; medium spiny neurons located in the caudate and putamen (collectively known as the striatum) are affected early on in the disease process, followed by loss of neurons in other brain areas [3,4]. The neuronal degeneration is manifested symptomatically through progressive motor dysfunction and cognitive impairment. Psychiatric and affective symptoms are also common [5]. The motor dysfunction in HD consists of both disordered and poorly coordinated voluntary motor function, and involuntary movements, synonymous with “chorea” in HD [6]. Generally, physiotherapy guidelines have focussed on exercise therapy to maintain, correct, and coordinate voluntary movements in those with HD [5]. Aquatherapy has been suggested as a means for HD patients to perform recommended exercise therapies [7].

Aquatherapy – also known as aquatic therapy, hydrotherapy, or pool exercise – is used in many different rehabilitation programs. Various types of water-based therapy have been used for the purpose of rehabilitation and treatment of chronic illness since the early 1900’s [8]. Water acts as a unique medium allowing for weight-bearing exercise without stressing the joints, movement and stability drills without the fear of falling, and multi-directional resistance training without the need for free weights or bands. The properties of the water itself are manipulated for different types of therapies. Temperature, for example,

is adjusted in therapy pools for muscular pain (10°C – 15°C) versus long immersion stretching programs (33°C – 36°C) [8]. Rehabilitation based aquatherapy, is most commonly performed in a warm (above 30°C), shallow (chest-deep) pool, with programs involving a combination of exercise modalities including aerobic training, stretching, range of motion (ROM) training, strength/resistance training, and balance/stability training [9]. The potential benefits of water exercise are important factors that have led to the development of aquatic exercise and/or rehabilitation programs for various special populations [9-11].

The present study was conducted to evaluate the feasibility, safety, and patient perceptions of aquatherapy as an exercise intervention for HD. Recent pilot research in Parkinson’s disease (PD) has shown aquatherapy to be safe, feasible, and to significantly improve quality of life. Additionally, resistance based programs in PD have demonstrated some improvement in functional mobility (as measured by standardized PD rating scales) and in postural stability [12,13]. Exercise therapy in mid-to late-stage HD populations is limited due to mobility and risk of falls, however aquatherapy programs in PD have shown success in a reduction of risk and fear of falling in this similar population [13]. Very few HD specific exercises interventional studies have been performed, however respected committees in the field have called for

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increased physiotherapy and exercise therapy in this population [14]. The Physiotherapy Working Group of the European Huntington's Disease Network (EHDN) suggests targeting balance, coordination, core stability, functional and task specific training, and ambulation/gait training in HD physiotherapy programs, however more specific recommendations have not yet been made [15,16]. Motivated by the emerging evidence in PD, we set out to evaluate the feasibility, safety, and patient perceptions of aquatherapy as an exercise intervention for HD.

## Method

### Facility

The study was conducted at a long-term residential care facility, The Evergreen Hamlets at Fleetwood in Surrey, British Columbia, Canada from July 17<sup>th</sup> – August 22<sup>nd</sup> 2013. The therapy pool was located at the facility; the 3x4m pool was uniformly 1.2m deep and heated to 33 – 34.5°C. The pool was accessible by a staircase equipped with railings on either side, as well as a lift that could be used for the safe transfer of participants who were unable to ambulate into or out of the water. The lift (Hygienic and Hammock Slings, ArjoHuntleigh, Magog Quebec) moved in two directions (up and down, and forwards and backwards) to allow participants to be lifted from their chairs into the pool and vice versa. Mesh slings were used to hold participants on the lift for entry into and exit from the pool. One care-aid was required to assist in transporting study participants.

### Participants

The Evergreen Hamlets at Fleetwood has a total of 20 HD residents and an existing aquatherapy program open to all residents at the facility. Eight HD residents were excluded from this total population based on aggression/advanced disease (requiring more than two staff members to transport to/from and monitor in the pool). The study aquatherapist approached the remaining 12 HD residents for consideration of study participation, six declined, and informed consent for participation in the six week pool therapy program was obtained from the remaining six. All participants in the aquatherapy study (represented as P1 – P6 in this article to protect anonymity) were determined to be mid- or late-stage HD. HD staging was determined by the Total Functional Capacity Rating Scale (TFC) of the Unified Huntington Disease Rating Scale (UHDRS). The scale rates a person's level of independence in five domains: occupation, ability to manage finances, ability to perform domestic chores, ability to perform personal activities of daily living, and setting for level of care [17,18].

Following the six week HD-specific aquatherapy program, participants were asked to participate in a follow-up study survey. Participation in the study survey required residents to be: (1) at least

18 years of age, (2) able to provide written consent or have a substitute decision maker who can, (3) carrying the abnormal HD gene and show symptoms of HD, (4) able and willing to comply with study requirements, (5) of stable medical, psychiatric and neurological health at the time of enrollment, (6) not abusing drugs and/or alcohol which may cause failure to comply with study procedures, and (7) living at Evergreen Hamlets throughout the timeline of the study. Participants were excluded from the study if they were (1) deemed too aggressive or impaired by Evergreen Hamlet staff, (2) younger than 18 years of age, (3) unable or unwilling to provide written consent and had no substitute decision maker, (4) unwilling to comply with study requirements, or (5) likely to be non-compliant with study procedures due to drug and/or alcohol abuse. Demographic data about participants' age, sex, and living status was collected, all relevant participant characteristics are described in Table 1.

### Procedure

Due to the heterogeneity of abilities of program participants, the aquatherapy programs used in this study were tailored in difficulty to individual participants. Programs were developed based on general physiotherapy guidelines as described by the Physiotherapy Working Group of the EHDN in their Physiotherapy Guidance Document from 2009 [15,16]. This document suggests that programs for HD target the following specific areas: balance, coordination, core stability, functional and task specific training, and ambulation and gait training [15,16]. Each program was developed to span the 30 minute pool session and was progressed as necessary throughout the study.

Participants were offered twice-weekly pool sessions for a 6 week period, amounting to a total of 12 possible pool sessions. Pool sessions were conducted by a trained aquatherapist (also a certified lifeguard) and assisted by a care-aid for entry and exit. All participants wore some type of floatation aid (i.e. a lifejacket or aqua jog belt) for safety, and pool noodles were used for additional support for some participants. Sessions were conducted one-on-one with each participant and the aquatherapist. Each program involved a series of exercises (based on previously discussed recommendations) sandwiched between a brief warm-up and a cool-down. Some examples of the types of exercises involved include: sit-to-stands, walking drills, squats, kicking, band exercises, ball tosses, and stretching.

Programs were progressed by adding resistance to movements, increasing number of sets or repetitions of each exercise, providing less assistance during balance drills, and increasing time of aerobic training (such as walking and kicking). During each session, the aquatherapist would ask participants (those who were able to respond) if there was any muscle soreness since the last session. The aquatherapist also kept a record of any injuries, both minor and major, that occurred in the pool

Participant	General Information	Disease	CAG Repeat Length	Total Functional Capacity (TFC of the UHDRS)	HD Stage	Independent Ambulation
	(Gender, Age in years)	Onset				
	(Year, Age in years)					
P1	Female, 46	2000, 34	21/49	0	Late	N
P2	Male, 28	2006, 21	17/60	1	Mid-late	Y
P3	Female, 51	2000, 39	17/40	0	Late	N
P4	Female, 56	1998, 41	18/42	3	Mid-late	Y
P5	Female, 51	1999, 37	19/43	1	Mid-late	Y
P6	Male, 57	2005, 50	23/43	0	Late	N

CAG = cytosine-adenine-guanine ; TFC = total functional capacity ; UHDRS = the Unified Huntington Disease Rating Scale

**Table 1:** Participant Characteristics

during aquatherapy sessions. For purposes of this study, to distinguish between major and minor, a major injury was defined as any injury requiring immediate medical attention by a physician or transport to the Emergency Department.

### Data collection

Immediately following the 6 week aquatherapy program, semi-structured interviews were conducted with each participant and a caregiver when available. Interviews were conducted by two individuals, not directly associated with the aquatherapy program, so as to avoid unnecessary study bias. The interview consisted of a short questionnaire, modelled after the one used by Khalil et al., to assess adherence to a home-based exercise DVD in people with HD (Appendix 1) [19]. This questionnaire was used as it has already been tested in a similar HD population to evaluate an exercise intervention. Additionally authors felt the survey length and difficulty was appropriate for the current study population. The semi-structured interviews were used to better understand participants' individual experiences with the program and explore factors that may have encouraged or hindered involvement. The questionnaire contained both open and closed questions for discussion purposes. Caregivers or family members were present for interviews with three of the six participants. In the three interviews with caregivers or family members present, they were encouraged to participate or share their own observations of the program along with the participant. The study team thought this additional perspective/information would enhance results obtained from the interview process, particularly if speech of the participant was an issue or if the caregiver had witnessed any of the aquatherapy sessions. All interviews lasted for approximately 30 minutes and were audio recorded to ensure that all opinions expressed were captured. Full transcription of interview audio recordings was completed to ensure trustworthiness of the data and avoid selective recording of the information.

## Results

### Exercise adherence (Table 2)

Adherence for 3 of the 6 participants is low, due to the mechanical failure of the pool lift. The lift, required for non-ambulatory participants, was broken for one week during the aquatherapy program, so 3 participants were forced to miss 2 aquatherapy sessions each. Adherence rates of participants P1, P3, and P6 recorded as 50%, 75%,

and 75% respectively are the values affected by mechanical failure of the lift. If n values are adjusted to 10 instead of 12 for the maximum possible sessions attended, adherence for these 3 participants becomes 60%, 90%, and 90%.

Values for aquatherapy adherence as well as explanations for missed sessions are described in table 2. This style of reporting adherence was modelled after a study by Khalil *et al.*, to assess adherence to an exercise DVD program [19].

### Semi-structured interviews

All six participants and/or their family members reported that they enjoyed the aquatherapy sessions and would definitely continue their participation in aquatherapy if they were given the opportunity to do so. All participants agreed that the personalized exercises in the program were easy to follow, and suitable for them. Specific results gleaned through therapist notes and audio recorded interviews, demonstrate five key themes regarding the use of an aquatherapy program in people with mid to late stage HD: the program was enjoyable, it improved mood and quality of life, it is safe and feasible, it improved sleep, and it improved self-reported motor function (or physical conditioning). Generalized themes have been drawn and illustrated in Table 3.

## Discussion

### Enjoyment

All six participants indicated that they found the aquatherapy sessions enjoyable and well-tailored to their abilities. Participant 3's companion said:

"She (P3) did really well, maybe because it was so one-on-one, and (the therapist) talking right in (her) ear ... It was nice, because ... I guess it just stimulated her (P3) maybe. ... And she liked the attention, talking one on one..."

In discussion with the Aquatherapist, she commented:

"I think that they (participants) felt really independent in the water compared to out, ... a lot of people of the ones who could talk would say like "I feel so strong", or ... "I feel so good" ...even P3 walked on Monday. She hasn't walked in a year, and she stood up and was walking in the pool ... It was crazy, and her face was ... she doesn't usually have an expression, but she was, like, making noise and being excited."

Participant	Reported Participation (Maximum Adherence = 12 Sessions)	Adherence Rate	Reasons for Nonadherence
P1	6	50%	On outings, mechanical failure of lift
P2	11	92%	On outing
P3	9	75%	Unwell, mechanical failure of lift
P4	11	92%	On outing
P5	6	50%	Refused to come
P6	9	75%	Unwell, mechanical failure of lift

Table 2: Characteristics of Adherence to the Aquatherapy Program.

Participant	General Information	QOL	Mood
P1	Female, 46 years	Much better	Much better
P2	Male, 28 years	Better	Better
P3	Female, 51 years	Much better	Better
P4	Female, 56 years	Much better	Better, calmer
P5	Female, 51 years	Better	Much better
P6	Male, 57 years	Undecided	Better

Table 3: Participant Responses – Quality of Life, Mood, Sleep.

When asked about study repetition, all subjects stated that if the program was offered again, they would look forward to participating.

### Mood and quality of life

Participants were directly asked to rate (on a scale of much worse to much better) the impact of the aquatherapy study on their mood and quality of life (QOL), with the majority reporting improvement in both mood and QOL. Full responses are outlined in table 3. Participant 2's companion said:

"I found that when he is finished this thing (aqua-therapy session) he had more energy, and he seemed to be pleased with it because it gave him a sense to being able to do things without help, ... I watched him one time and he's in the water and ... he's walking (with) no walker and he was bouncing and not falling, and he just loved it, it made him feel happier."

Participant 4 agreed:

"(The pool sessions) made my moods better. (It) helped my sleep. I (felt) calmer"

Mood and quality of life are important indications of a person's mental health and are therefore critical to understand and monitor, particularly in those with degenerative disease. These factors have been extensively studied using exercise interventions in both healthy and clinical populations, and consistently found to be effected by exercise [10, 20-22]. A randomized control trial of the effect of exercise on quality of life in healthy, sedentary women showed a dose dependant relationship between exercise and improvement in quality of life, and these results have been reproduced in populations of various illness and diseases [20-22]. Improvement in mood and/or quality of life was important findings in the present study.

### Feasibility and safety

The aquatherapy program was a feasible intervention in people with mid to late stage HD with staffing by one care aid and one aquatherapist for participant transportation and exercise programming. The aquatherapy program was considered a safe intervention in people with mid to late stage HD, as determined by injury occurrence during aquatherapy sessions. The aquatherapist reported one incident of a stubbed toe on the pool staircase, while no participants reported any accidents or injuries when asked about "soreness" and "injury" at every aquatherapy session. Additional preventative safety precautions were taken, including: having a trained and certified lifeguard instruct aquatherapy sessions, and equipping participants with one or more flotation device(s) (either an aqua-jog belt or a lifejacket with additional various floatation aids as required) at all times in the pool. These precautions were taken to minimize the risk of near drowning and/or choking experiences. When asked directly, 5 of 6 participants and/or caregivers denied any safety concerns/misgivings regarding the aquatherapy sessions. Participant 1's companion said:

"My concern was that if she (P1) got her head in the (pool) that ... she'd had an ear infection, ... over the winter she had a lot of ear problems and they assured me that ...she, you know, wouldn't put her face or head in the water, and it's worked out fine..."

No, (P1 is) probably safer on the water than on land as long as you're with a therapist"

### Sleep

An important but unexpected finding from the aquatherapy study

was the positive impact the program had on participants' sleep. This result was communicated to study staff during the interview process by five of the six participants (one participant already enjoyed good quality sleep prior to therapy).

Participant 2 said:

"It was easier to fall asleep (after the exercises)."

Participant 3's companion commented:

"She (P3) would be really tired after (the aquatherapy session), she would fall asleep on the way home"

Sleep disturbance is a common complaint in those with more progressed stages of HD [23]. The exact physiology responsible for changes in sleep and circadian rhythm in people with HD is not fully understood, however practically speaking, patients experience exacerbation of HD symptoms due to sleep disturbances therefore sleep improvement is a beneficial therapy in this population [23]. Studies have shown shorter time to fall asleep and longer total sleep duration as benefits to chronic exercise, as well that improvement in mood through exercise may be related to sleep improvements [24]. The aquatherapy experience at Evergreen supports the concept that sleep improvements observed in healthy chronic exercisers may be extrapolated to those with HD.

### Physical conditioning

Another important finding in this study was the positive impact the aquatherapy program had on participants' general physical conditioning as observed by companions of participants. This is quite encouraging, given the short assessment period of the study (maximum 12 sessions over six weeks).

Participant 1's companion said:

"I did notice that she (P1) is sitting up a lot more upright in her wheelchair and that can be because her core muscles were getting weaker and I think they (are) strengthened into the pool. ...She is keeping her head up, you may have noticed today, even."

Participant 3's companion said:

"Yes, there is that feeling (that) she (P3) can walk. (The therapist) was saying she is walking again. I haven't seen her do that ... on her own in the pool. It just has to feel good all over to be able to stand up, so I think that would be the best part of it ..."

This finding may suggest that aquatherapy might have a beneficial impact on motor symptoms of HD, but firm conclusions cannot be drawn from this small pilot study.

Results of this study, confirm that all participants adhered to the study (as assessed by an adherence rate of greater than or equal to 50%). Only one of six participants ever refused to attend aquatherapy sessions when they were offered, often based on psychological feelings of apathy, anxiety, and/or irritability. Otherwise reasons for missed sessions by all five other participants include illness, being away from the facility on outings, and mechanical failure of the pool lift. It was noted that compliance was positively affected by the presence of a familiar caregiver at the aquatherapy sessions. This may mitigate some of the psychological stress participants may experience when confronted with new experiences or environments.

### Study limitations

The small sample size is the primary limitation of this study, as

more complete conclusions would require a larger sample size. Ideally, a longer aquatherapy intervention in a more uniform population (for example one with more similar HD staging, symptom presentation, and age) would have allowed for implementation of a standardized aquatherapy and therefore a stronger ability to compare performance and experience between participants. It is suggested that a larger follow-up study be conducted in a uniform HD population to assess efficacy of aquatherapy for sleep, enjoyment, quality of life, mood, and motor symptoms in HD.

Due to the range of abilities in communication between participants, the audio recorded survey was employed as the best means of capturing the data regarding every participant's experience. Because of the structured set of questions asked, researchers were able to elicit responses on topics meaningful to the study. Disease-specific aspects of concern here include barriers to communication such as speech production difficulties, impaired understanding, and cognitive impairment affecting the ability to remember aquatherapy sessions and evaluate them at a future date. These limitations are common to any questionnaire-based study targeted at the HD population, and were partially addressed with the involvement of a caregiver both during the aquatherapy sessions, and the study interview/questionnaire. It was found that the caregiver could provide additional feedback regarding the participant's experience during therapy, and well as individual level of suitability of the aquatherapy. Aquatherapy research in the PD population does suggest that caregiver adherence largely influences participant adherence in exercise programs [25].

Although many precautions (such as having trained and certified staff, using floatation devices, etc.) were taken to minimize risk to the participant group in the current study, the very nature of pool exercise poses inherent risk to participants that may be reduced but not eliminated. It is thought, however, that with appropriate precautions to reduce the inherent risk of water-based exercise coupled with the benefit of a falls reduction risk in water, aquatherapy offers an appropriate risk-benefit ratio for participants.

A final risk to consider is to the therapy staff themselves secondary to the unpredictable aggression and irritability in the mid- to late-stage HD population. These factors may make some people with HD unsuitable for the aquatherapy environment.

## Conclusions

This study was able to assess safety, feasibility, and enjoyment of an aquatherapy program for people with mid- to late-stage HD living in a long-term care facility. There are few programs available for this population, so establishing positive findings for all three aforementioned variables was a success for this study. As mentioned, future research aimed at determining efficacy of an aquatherapy program for people with HD may be relevant to clinicians, caretakers, and those living with HD, particularly if results show any impact on symptomatic management or disease progression.

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