Case Series
An Aquatic Physical Therapy Program for Adults with Severe-Profound Developmental Disabilities

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Abstract

Background and purpose. This case series describes the use of aquatic physical therapy for adults with severe-profound developmental disabilities. The purpose of this study was to expand on the current literature to determine the effectiveness of aquatic physical therapy for such population through the assessment of passive range of motion (PROM), muscle tone, volition, function, burden for care, and pain.

Case description. Thirteen individuals participated in the study (5 females and 8 males). The median age was 37 years and 10 months. All carried a clinical diagnosis of spastic quadriplegia. None of the participants were able to walk independently, and all used a wheelchair for their primary means of functional mobility. Six were able to ambulate with assistance. The degree of mental involvement was severe in 7 and profound in 6. Each participant participated in 2 thirty-minute aquatic physical therapy sessions per week for 8 weeks. Interventions used included the Bad Ragaz Ring Method, upper extremity and lower extremity stretching/PROM, and functional task training. All variables were measured at baseline (1 week prior to the intervention phase), once a week during the 8-week intervention phase, and at weeks 1, 3 and 5 during the follow-up period.

Outcomes. PROM, volition, muscle tone, and caregiver evaluation scores (burden of care) showed significant improvement from week 1 to week 8. During the follow-up period all of the parameters maintained their improvements from the intervention phase. Functional improvements varied based on each participant's ability to ambulate, stand or sit. Although the changes in pain parameters were not statistically significant, the MCID for pain can be observed through improved subjective reports of pain, improvements in functional tasks and improvements in caregiver evaluation scores.

Discussion. Aquatic physical therapy is an effective intervention to improve PROM, volition, muscle tone, ease of care, and function for those with severe-profound developmental disabilities.

Key words: Aquatic physical therapy, developmental disability, cerebral palsy, Bad Ragaz Ring Method.

Introduction

Along with the increase of life expectancy for those in the general population, adults with developmental disabilities are showing an increase in life expectancy as well.[1-6] It has been estimated that there are approximately 650,000 adults, age 60 years and older with disabilities, some of which reaching their 7th or 8th decade of life. Due to advances in modern medicine and access to medical care, population projections are predicting that the number of adults with disabilities age 60 and older will double by 2030.[1-5]

Little is understood on how the aging process affects those with developmental disabilities. There is limited information on how older individuals with cerebral palsy (CP) maintain or lose function as they age and, little is known on how to guide and develop best practices to treat such individuals with age- associated problems.[1-5] However, studies have documented the importance of maintaining function for older adults with CP, as those who have lost their ability to walk by age 60 had poorer survival than that of the general population.[6]

In addition to the diagnosis of CP, these individuals often present with secondary conditions such as pain, hip and back deformities, bowel and bladder problems, nutritional problems, respiratory complications, poor dental health, gastroesophageal reflux symptoms, and progressive neurologic dysfunction.[5,7] A decrease in function secondary to muscle weakness and other biomechanical alterations, such as degenerative joint diseases and osteoporosis, have been observed in this population, which may accelerate the normal aging process.[2,7]

There is little information about means to maintain mobility, strength and endurance over a lifetime for an adult with CP.[5] However, exercise is a well- known health-promoting behavior and its positive effects have been demonstrated in persons with disabilities.[8-13] Aquatic physical therapy has been found to be a beneficial intervention for those with developmental disabilities, to improve flexibility, respiratory function, muscle strength, gait, and gross motor function.[10] Exercise in the water provides more freedom for those with disabilities when compared to exercise on land. The buoyancy of the water decreases the influence of gravity and provides increased postural support. The water provides a suitable exercise environment for those with mobility impairments as the negative influence of poor balance, poor postural control, and excessive joint loading are reduced.[10]

Currently, there is limited research to support the use of aquatic physical therapy for adults with severe-profound developmental disabilities. Vogtle et al found that an aquatic program employing water shiatsu and the Halliwick method was effective for improving passive range of motion (PROM), decreasing pain and providing a pleasurable social experience in adults with CP.[14]

The purpose of this study was to expand on the current literature to determine the effectiveness of aquatic physical therapy for adults with severe- profound developmental disabilities through assessment of PROM, tone, volition, function, burden of care, and pain.

Methods

Aquatic intervention was administered, and data were collected between January and August of 2013 which included 2 separate 8-week intervention phases. All participants resided and attended the developmental training program at Marklund in Geneva, Illinois. Marklund is a nonprofit organization located in Bloomingdale and Geneva, Illinois that serves infants, children, teens, and adults with severe and profound developmental disabilities and special healthcare needs. Informed consent was obtained from the guardian(s) of each participant and the Marklund Human Rights Committee approved the research protocol.

Participants

Thirteen individuals participated in the study (5 females and 8 males). The age range was 26 years and 5 months to 49 years and 7 months, with a median age of 37 years and 10 months at the time of the study. Participants were excluded from the study if their medical status was not stable and if they had a history of negative behaviors and frequent incontinence while in the aquatic environment. All individuals have participated in the Marklund aquatic therapy program prior to partaking in the study. Each received aquatic therapy 2 times per week on 2-3 non-consecutive months per year.

All participants carried a clinical diagnosis of spastic quadriplegia. None of the participants were able to ambulate independently, and all used a wheelchair for their primary means of functional mobility. Six were able to ambulate with assistance. Eight had epilepsy, 2 were being fed by gastrostomy tube and ten were fed orally with assistance. The degree of mental involvement was severe in 7 and profound in 6. None of the participants had a tracheostomy.

The causes of their neurologic diagnoses were cerebral palsy (10 participants), encephalitis shortly after birth (1 participant), tuberculosis meningitis at 2 years of age (1 participant), and asphyxia due to airway obstruction at 2 years of age (1 participant).

Six were not receiving any medications for spasticity. Two were being treated with chlorazepate, 2 with diazepam, 1 with dantrolene sodium, 1 with baclofen and 1 with methocarbamol. There were no changes to any spasticity medications during the course of this study.

Procedure

Muscle tone, PROM, pain, volition, function, and ease of care were examined. All variables were measured at baseline (1 week prior to the intervention phase), once each week for the duration of the 8-week intervention phase, and at weeks 1, 3 and 5 following the intervention phase. In addition, muscle tone and PROM were measured on land, immediately prior to each therapy session. Measurements were performed by 2 physical therapists and 1 student physical therapist.

Muscle tone was measured using the Modified Ashworth Scale (MAS). Muscle groups measured included the bilateral elbow flexors and the bilateral knee flexors or extensors. The muscle group that was measured at the knee was the group that presented with more muscle tone when compared with the antagonist. The MAS has been shown to have an acceptable intraclass correlation coefficient (ICC > 0.8) for test-retest and interrater reliability for individuals with developmental disability.[15]

PROM measurements included shoulder, elbow, knee and hip flexion and extension. Measurements were preformed consistent with the methods established by Norkin and White.[16] Goniometry has been determined to have high validity with an intraclass correlation coefficient of 0.99.[17] Factors that have been shown to improve reliability include use of another person to help stabilize the extremity during measurement and having the same tester perform measurements pre and post.[16] Testers were consistent for each participant in this study and in some cases an additional person was used to stabilize the extremity.

In cases where PROM improved, that motion was scored as +1. When the number decreased, it was scored as -1. For each individual there were 16 motions assessed. The final score was determined by adding the number of +1, to the number of -1, to the number of no change motions. For example, if 1 participant improved in 7 motions, decreased in 2 motions and 7 motions did not change, the score would be +5. Dividing by 16 to determine the average, gives a result of +0.313. If there were improvement in all motions, the score would be +1.000. If there were a decrease of all motions, the score would be -1.000. A similar equation was used to quantify tone.

Pain was measured via the Non-Communicating Adult Pain Checklist (Appendix A). With this objective measure, pain is rated using a four-point Likert scale with 6 categories of 18 items including vocal reaction, emotional reaction, facial expressions, body language, protective reaction, and physiological reaction. The tool was found to have high internal consistency ($\alpha = 0.77$) and sensitivity (standardized response mean of 1.20-2.07).[18,19] In addition, higher intra and interrater reliability has been established with an ICC of 0.94 and 0.91-0.92 respectively.[19]

Volition was measured using the Volitional Questionnaire (VQ) (Appendix B) which is a tool designed for lower functioning adults with no to limited communication. The VQ has been used in individuals with mental illness, dementia, head injury, stroke, intellectual disability, and learning disabilities.[20]

The subject is observed in an occupation (eg, work, leisure, daily living task), which can be done during therapeutic treatment sessions.[20] Each item is scored on a four-point scale which indicates whether the person is passive, hesitant, involved, or spontaneous in exhibiting the observed behavior. The scores on the items can be summed to yield a measure of the amount of positive volitional behavior.[21] The VQ has been studied for internal consistency and determined to have good construct validity and to be a good measure of volition.[21,22]

For this study, the VQ was administered once a week with a new task in and out of the aquatic environment for each participant. When possible, participants were given the choice of which task they would like to participate in (dependent on the concentration of disability). Participants completed tasks such as selecting objects based on color or size, reaching for an object, sorting objects, throwing a ball in a hoop, and following multiple step commands.

Function was assessed in water and on land. The functional tasks assessed were determined based on the participant's ability to sit, stand or ambulate. Participants were tested in the water for 10 minutes. Ambulation was quantified using the number of steps taken. Standing was measured based on the amount of time they were able to maintain standing with upper extremity support. The time was stopped if lower extremities buckled before the 10-minute time limit. Those who utilized sitting as their task was measured based on the amount of time they were able to maintain sitting with upper extremity support. The time was stopped if they lost their sitting balance and required assistance to recover.

Functional tasks were also assessed on land. The amount of time/steps for measurement was dependent on the participant's tolerance for the activity. While ambulating, the number of steps was counted until the participant's second request to stop was given (to allow for therapists to provide verbal cues of encouragement to continue). Standing was ceased when 2 requests to stop were given by the participant or their lower extremities buckled (whichever came first). Time was used to quantify sitting with the time being stopped when the participant was unable to maintain their sitting balance.

Ease of care was measured using a caregiver questionnaire (Appendix C) immediately before and after each aquatic session. The caregiver questionnaire was derived from a study that focused on aquatic physical therapy as an intervention for those with CP living in group homes.[14] The six-point questionnaire was completed by caregivers and measured each participants ease of transferring, dressing and bathing.

Intervention

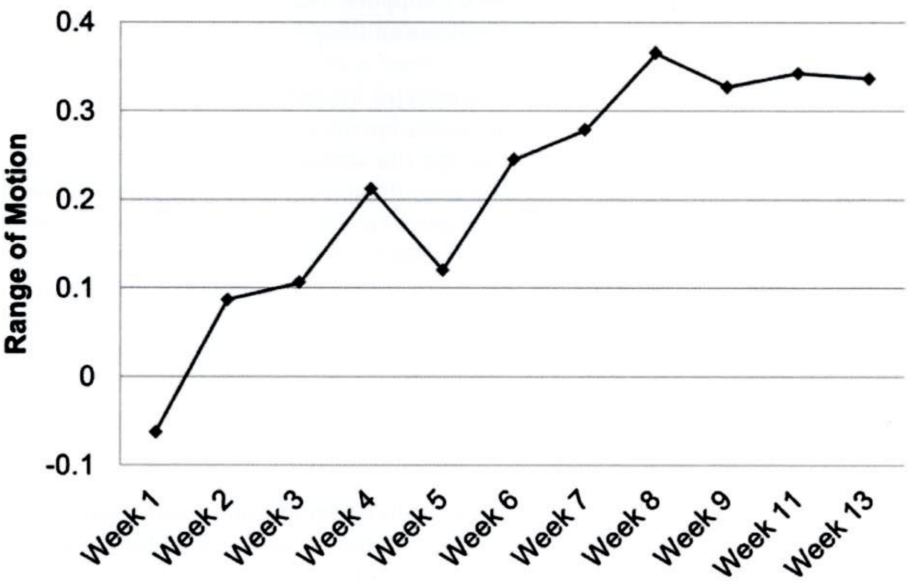
Each participant partook in 2 thirty-minute aquatic physical therapy sessions per week for 8 weeks. Water temperature was maintained at 92-93°F and the environment was maintained with only day light (from windows) and without music.

The program was overseen by 2 physical therapists with assistance given from physical therapist assistants, occupational therapist assistants, and therapy aides. Those who assisted the physical therapists with intervention were trained on the specific techniques prior to the beginning of the intervention phase. All sessions were one-on-one between the therapist and participant. One to 2 additional therapists or aides were present during each session to assist with stabilizing extremities during stretching and ROM measurements, positioning, entering/exiting the water, dressing, and bathing (postintervention).

Each thirty-minute aquatic physical therapy session was divided into three 10-minute segments. One 10-minute segment utilized the Bad Ragaz Ring Method, another for upper extremity and lower extremity stretching/PROM measurements and another for functional task training/measurement.

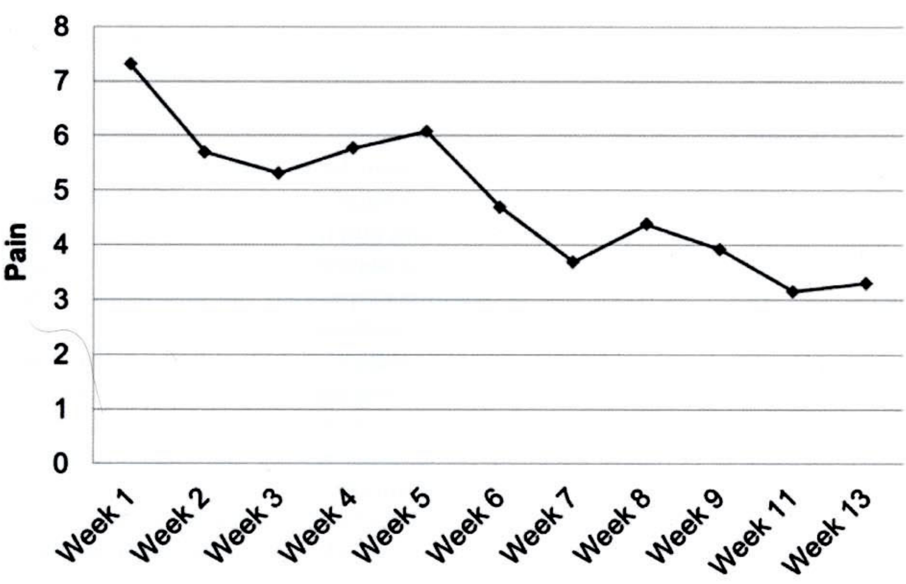
The Bad Ragaz Ring Method is a one-on-one horizontal treatment technique in the aquatic environment in which the participant is supported floating in a supine position with assistance from a therapist and flotation rings around the participant's neck, pelvic region, knees, and/or ankles.[23] The Bad Ragaz Ring Method is used for muscle reeducation, strengthening, spinal traction/elongation, relaxation,

Figure 1. Range of Motion



The mean score of ROM of the 13 participants, over the study time period. Active intervention was weeks 1 through 8, follow-up was weeks 9 through 13.

Figure 2. Pain



The mean score of pain of the 13 participants, over the study time period. Active intervention was weeks 1 through 8, follow-up was weeks 9 through 13.

and tone inhibition in the water.[23] In this study, the method was used primarily for spinal traction/elongation, relaxation and tone inhibition.

Statistical Analysis

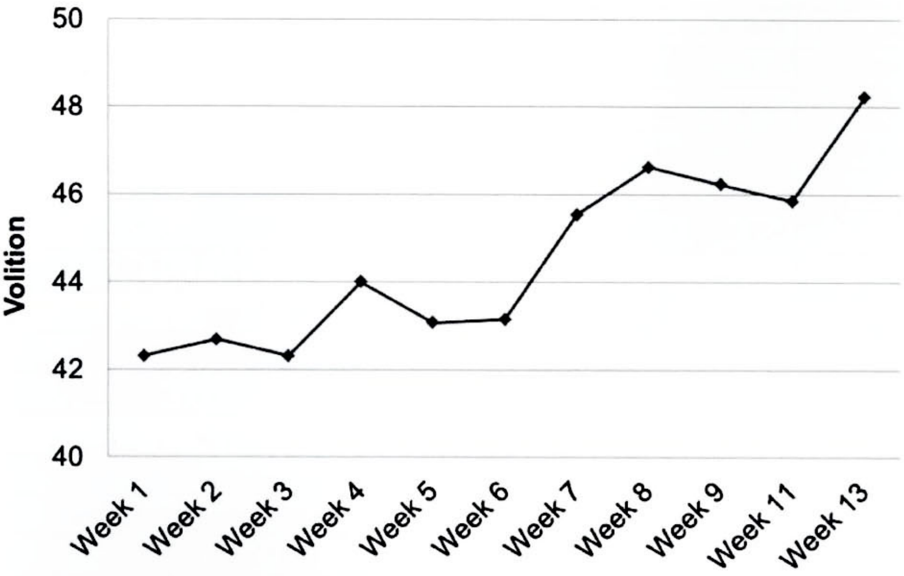
Five parameters namely PROM, pain, volition, muscle tone, and ease of care, were measured. All data were screened for outliers and normality assumptions. Two sets of analyses were performed for each outcome measure except caregiver evaluation. First, for all outcomes, the time course from baseline to the end of the therapy program was examined using mixed models with repeated measures, with week as the within-subject factor, and the outcome measures at each week as the dependent variables. Second, for range of motion, pain, volition, and tone, a similar set of mixed models examined the change during the follow-up period. All tests were 2-tailed and an alpha level of 0.05 was adopted for all inferences. As the participants of this study were unable to report on the minimal clinically important difference (MCID), it was determined using a Delphi approach to form a consensus between the authors of this study.

Results

Figures 1-4 presents the outcome measures at each time point. Of the 5 studied parameters, all but 1 showed significant improvement from week 1 to week 8. PROM increased from -0.06 (0.22) to 0.37 (0.26), $F(7,12) = 6.38$, $p = .003$; volition improved from 42.3 (12.8) to 46.6 (11.2), $F(7,12) = 6.33$, $p = .003$; muscle tone improved (decreased) from -0.10 (0.59) to 0.31 (0.70), $F(7,12) = 6.22$, $p = .003$; and caregiver evaluation scores improved from 12.7 (5.6) to 10.7 (5.0), $F(7,12) = 3.02$, $p = .04$. Pain scores decreased from 7.3 (7.6) to 4.4 (3.0), $F(7,12) = 2.31$, $p = .10$. However, changes for pain were not statistically significant. The MCID for pain can be observed through improvements in caregiver evaluation scores and functional tasks during the intervention phase. During the follow-up period, none of the parameters showed a significant change between postintervention and follow-up (ROM: $F(3,12) = 1.1$, $p = .4$; pain: $F(3,12) = 1.3$, $p = .3$; and volition: $F(3,12) = 2.2$, $p = .14$; muscle tone: $F(3,12) = 1.8$, $p = .2$).

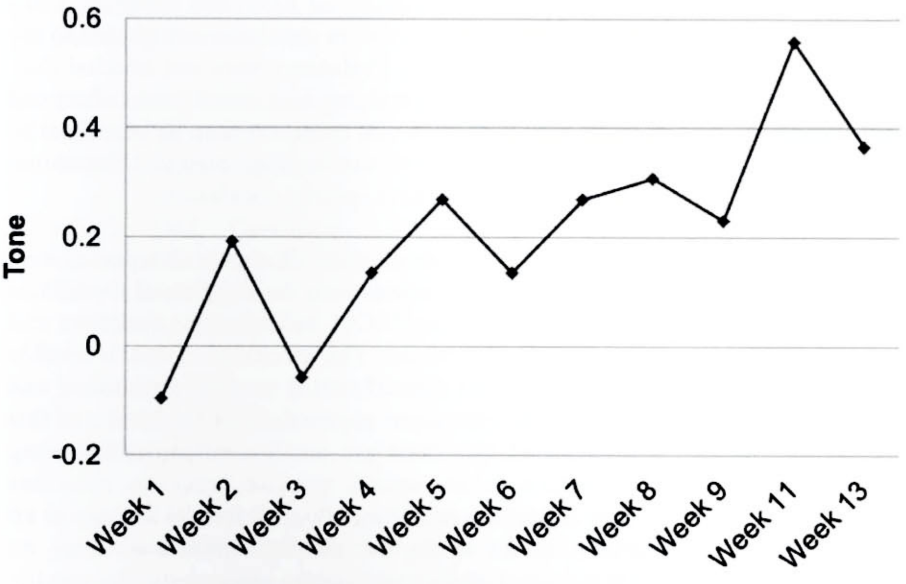
Functional task (Table 1) was not analyzed statistically as the task was dependent on the participant's functional ability to ambulate, stand or sit and was not consistent across all participants. In the water, improvement/decline was determined by assessing abilities in week 8 compared to week 1 during the intervention

Figure 3. Volition



The mean score of volition of the 13 participants, over the study time period. Active intervention was weeks 1 through 8, follow-up was weeks 9 through 13.

Figure 4. Muscle Tone



The mean score of muscle tone of the 13 participants, over the study time period. Active intervention was weeks 1 through 8, follow-up was weeks 9 through 13. Note: The positive slope of the graph indicates that the mean score of tone decreased.

phase. On land, improvement/decline was determined by assessing abilities in week 8 compared to week 1 during the intervention phase and in week 5 compared to week 1 during the follow-up period. Of those participants in which ambulation was assessed, 3/7 (42.9%) demonstrated improvements during the intervention phase on land, 2/7 (28.6%) demonstrated improvements during the follow-up period on land, and 3/7 (42.9%) demonstrated improvements while in the aquatic environment. Of those participants in which their ability to stand was assessed, 5/5 (100%) demonstrated improvements during the intervention phase on land, 3/5 (60%) demonstrated improvements during follow-up period on land and 2/5 (40%) demonstrated improvements while in the aquatic environment. Only 1 participant's ability to maintain sitting balance was assessed, improvements were seen during the intervention phases on land and in the aquatic environment, no changes were observed during the follow-up period on land.

Discussion

The results of this study suggest that aquatic physical therapy is an effective intervention to improve PROM, volition, tone, ease of care, and function for adults with severe-profound developmental disabilities. Although pain scores showed a decrease in overall pain, this improvement did not reach statistical significance. However, clinically significant pain reduction was reported by caregivers and physical therapists and was observed via improved subjective reports of pain (verbally or through facial expression), improvements in functional tasks and improvements in caregiver evaluation scores.

During the follow-up period all of the parameters maintained their improvements from the intervention phase. This indicates that improvements seen during the intervention period were maintained and did not return to their baseline value.

While assessing function, the greatest improvement in task was observed during the intervention phase. Improvements were seen both on land and in the water (except for standing) suggesting that aquatic intervention for functional task training was carried over to performance of the task while on land. In addition to improvement in the amount of steps taken or amount of time that the participant was able to maintain sitting/standing balance, decreases in the

Table 1. Functional Task Measures

Subject	On Land	Intervention Phase	Follow-up Period	In Water	Intervention Phase
1	Standing	+13 seconds (+8.7%)	-10 seconds (-5.8%)	Ambulating	+39 steps (+56.9%)
2	Standing	+85 seconds (+70.8%)	-299 seconds (-51.1%)	Standing	+120 seconds (+25.0%)
3	Standing	+179 seconds (+129.7%)	+157 seconds (+90.2%)	Standing	No change
4	Ambulating	-3 steps (-18.8%)	-11 steps (-20.8%)	Ambulating	- 3 steps (- 2.4%)
5	Ambulating	-3 steps (-7.1%)	+16 steps (+44%)	Ambulating	+290 steps (+223.1%)
6	Ambulating	+61 steps (+19.1%)	-61 steps (-14.8%)	Ambulating	+88 steps (+27.5%)
7	Standing	+207 seconds (+106.2%)	+40 seconds (+11.2%)	Standing	No change
8	Ambulating	+16 steps (+160.0%)	-5 steps (-45.5%)	Ambulating	-18 steps (-25.0%)
9	Ambulating	-11 steps (-19.3%)	-12 steps (-22.2%)	Ambulating	+16 steps (+21.3%)
10	Standing	+259 seconds (+157.0%)	+148 seconds (+55.8%)	Standing	No change
11	Ambulating	-18 steps (-8.7%)	-26 steps (-16.9%)	Ambulating	+114 steps (+90.5%)
12	Sitting	+300 seconds (+100.0%)	No change	Sitting	+24 seconds (+120.0%)
13	Ambulating	+4 steps (+5.2%)	+18 steps (+25.7%)	Ambulating	+35 steps (+27.8%)

+ indicates improvement during that phase, - indicates a decline during that phase. In the water, improvement/decline was determined by assessing abilities in week 8 compared to week 1 during the intervention phase. On land, improvement/decline was determined by assessing abilities in week 8 compared to week 1 during the intervention phase and in week 5 compared to week 1during the follow-up period.

amount of assistance the participant needed were observed in 2 participants.

With aquatic intervention, 1 participant gained the ability to ambulate with assistance on land and another demonstrated increased muscular endurance while performing functional gait training in the water.

Vogtle et al reported that a significant change in pain may not have been observed in their study secondary to stretching of soft tissue and related musculature around joints.[14] The fact that pain ratings in this study did not show a statistical change could be related to this premise as well.

As the caregiver questionnaire was designed solely for this study and a formal objective measure was not found, further research and investigation of objective measures to quantify concentration of care would help to support the reliability and validity of such measures.

Challenges encountered during the course of this study included ensuring adequate and consistent staffing, limiting disruptions while in the aquatic environment and determining an effective way to assess functional abilities.

Since there was no control group for this study, we cannot assume that improvements seen were solely from the aquatic intervention. On a daily basis, before and after participation in the study, each of the participants participated in a ROM program, activities to improve their function (ie, ambulation with a gait trainer, standing in a standing frame) and received optimal positioning for ROM and function. Thus, participation in these activities may have contributed to the outcomes of this study. Evaluators were not blinded during the course of the study so bias could have influenced outcomes as well. In future studies it may be beneficial to choose participants with similar diagnoses and functional abilities to provide a more specific conclusion.

In summary, this research study illustrates an aquatic intervention program for adults with developmental disabilities focusing on improving PROM, volition, tone, function, and decreasing burden of care. The specific plan used is feasible to implement in a clinical setting in a timely fashion and with minimal equipment required. Since the results of this study showed that there are positive outcomes following participation in an aquatic exercise program, clinicians and policymakers may view aquatic physical therapy as an intervention for adults with developmental disabilities. As there is limited high-concentration research on this specific population and intervention, further research is needed to support aquatic physical therapy as a possible intervention for these individuals.

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Appendix A: The Non-Communicating Adult Pain Checklist

The Non-Communicating Adult Pain Checklist						
Item #	**Sub Category**	**Item Description**	**Not at All**	**Just a Little**	**Fairly Often**	**Very Often**
1	**Vocal Reaction**	Moaning, whining, whimpering (fairly soft)	0	1	2	3
2		Crying (moderately loud)	0	1	2	3
3		Screaming/yelling (very loud)	0	1	2	3
4		A specific sound or word for pain (for example, a word, a cry, or type of laugh)	0	1	2	3
5	**Emotional Reaction**	Not cooperating, cranky, irritable, unhappy	0	1	2	3
6		Being difficult to distract, not able to satisfy or pacify	0	1	2	3
7	**Facial Expressions**	Furrowed eyebrows, raising eyebrows	0	1	2	3
8		A change in eyes (including squinting eyes, eyes opened wide, eye frowning)	0	1	2	3
9		Turning down of mouth, not smiling	0	1	2	3
10		Movements of the lips and tongue; lips puckering up, tight, pouting, or quivering, teeth grinding, tongue pushing	0	1	2	3
11	**Body Language**	Moving more or less	0	1	2	3
12		Stiff spastic, tense, rigid	0	1	2	3
13	**Protective Reaction**	Gesturing to or touching part of the body that hurts	0	1	2	3
14		Protecting, favoring, or guarding part of the body that hurts	0	1	2	3
15		Flinching or moving the body part away, being sensitive to touch	0	1	2	3
16		Moving the body in a specific way to show pain (eg, head back, arms down, curls up, etc.)	0	1	2	3
17	**Physiological Reaction**	Change in facial color	0	1	2	3
18		Respiratory irregularities: breath holding or gasping	0	1	2	3

Appendix B: Volitional Questionnaire

Indicators	Ratings				
Shows curiosity	P	H	I	S	N/O
Initiates actions/tasks	P	H	I	S	N/O
Tries new things	P	H	I	S	N/O
Shows preferences	P	H	I	S	N/O
Shows that an activity is special or significant	P	H	I	S	N/O
Indicates goals	P	H	I	S	N/O
Stays engaged	P	H	I	S	N/O
Shows pride	P	H	I	S	N/O
Tires to solve problems	P	H	I	S	N/O
Tires to correct mistakes	P	H	I	S	N/O
Pursues activity to completion/accomplishment	P	H	I	S	N/O
Invests additional energy/emotion/attention	P	H	I	S	N/O
Seeks additional responsibilities	P	H	I	S	N/O
Seeks challenges	P	H	I	S	N/O

Abbreviations: P = Passive, H = Hesitant, I = Involved, S = Spontaneous, N/O = No opportunity to observe

Appendix C: Caregiver Questionnaire

Today, *lifting/transferring* this client before aquatic intervention was:
Easy 1———2———3———4———5———6 *Difficult*

Today, *dressing* this client before aquatic intervention was:
Easy 1———2———3———4———5———6 *Difficult*

Today, *lifting/transferring* this client after aquatic intervention was:
Easy 1———2———3———4———5———6 *Difficult*

Today, *dressing* this client after aquatic intervention was:
Easy 1———2———3———4———5———6 *Difficult*

Today, *bathing* this client after aquatic intervention was:
Easy 1———2———3———4———5———6 *Difficult*