CASE REPORT

Aquatic Therapy for an ALS Patient

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This report focuses on one solution to the lack of options for persons disabled by a chronic degenerative disease. Persons with amyotrophic lateral sclerosis (ALS) often want to take an active role in maintaining physical fitness when traditional methods are no longer available to them, pursue rehabilitation goals after having been told they have "plateaued," or participate in activity that focuses on wellness rather than on disability. However, traditional recreation and fitness programs are often unavailable to this population because buildings are inaccessible and because staff members lack the knowledge to modify facility programs to include disabled participants. Therapeutic recreation and fitness programs are often available at rehabilitation hospitals but are frequently limited to that facility's inpatient and outpatient populations. Active community involvement to support treatment programs for this population may be nonexistent unless there is financial support and skill to implement such a program. The case discussed here may be valuable to occupational therapists who want to promote therapeutic programs for persons with a chronic degenerative disease while focusing on their individual interests and values.

Case Study

Sixty-two-year-old Charlie M, a high school graduate and World War II veteran, was found to have ALS in 1984 when he was 59 years old. Amyotrophic lateral sclerosis is a progressive degenerative disease of the nervous system, affecting both upper and lower motor neurons. The course of the disease is marked by progressive muscle weakness, atrophy, fasciculations, spasticity, and hyperreflexia. There is no known cure for the disease, and average survival time after the onset of symptoms is under 5 years.

Charlie first showed signs of weakness and fatigue in 1982 while working as an electrical mechanic for a utility company. He discovered he was unable to climb scaffolding he had climbed for 35 years. His symptoms were attributed to obesity and his grief following the illness and death of his father. As additional medical problems developed and physical deterioration occurred, Charlie began a weight loss program and was told to begin a steady regimen of walking or swimming. Because of his deteriorating gait, Charlie chose swimming, an activity he had enjoyed in the past. After several months of testing and daily swimming, Charlie's condition was finally diagnosed as ALS. He maintained his independence in self-care and continued to walk, at first with braces and a cane, then with a walker, and finally with a wheeled walker. He gave up independent swimming when he was no longer able to use the pool ladder.
Aquatic therapy has a long-established history and has been provided by physical, occupational, and recreational therapists in swimming pools, Hubbard tanks, and therapeutic pools since World War I (Reynolds, 1976). The goals of aquatic therapy have varied greatly. Aquatic programs can be categorized as either recreational, instructional, therapeutic, or integrated (Dulcy, 1983). In recreational programs, the emphasis is placed on developing play or leisure skills and having fun. Therapeutic aquatic programs focus on improving a patient's physical abilities, such as strength, range of motion, and endurance, by using water as a therapeutic medium. An integrated program uses swimming to promote a wide range of occupational therapy goals, focusing on the patient’s strengths and addressing his or her performance skills, habits, values, and roles.

Predictably, Charlie's condition worsened over the next 2 years. In April 1986, when he first enrolled in the Water Exercise and Therapeutic Swim (WETS) program, he was virtually quadriplegic and had trace-to-poor lower extremity muscle strength, fair-to-good strength in his shoulder muscles, and poor-to-fair strength in his wrist and hand muscles. There was noticeable tightness in his biceps bilaterally, but spasticity was not significant enough to be problematic. Charlie's respiratory status was compromised as a result of his weakened abdominal and thoracic muscles, and his ability to cough was impaired. Charlie was able to perform feeding and grooming activities independently with the aid of a minimum of adaptive equipment. He required moderate assistance for dressing and bathing. Charlie transferred with maximal assistance or via a Hoyer lift. His previous program of occupational, physical, and speech therapies had been curtailed to monthly evaluations during ALS clinic visits. Charlie had lost the ability to speak and to chew food. He communicated by spelling words in the air with his index finger and was able to handle a pureed diet well enough to avoid a gastrostomy or tube feedings. At home, Charlie was helped by his wife, Janet, a registered nurse. They had renovated the first floor and bathroom to make it accessible by wheelchair and they acquired an adapted van, hospital bed, shower chair, electric reclining chair, and a variety of adaptive equipment for maximizing Charlie's independence in activities of daily living (ADL). Janet performed a regular exercise program with Charlie to help him maintain his joint range of motion. Buoyed by a highly supportive family and his active involvement in the local chapter of the ALS Society, Charlie had maintained his cheerful disposition and positive outlook on life.

The program provides an optimal setting for addressing a wide range of occupational therapy concerns. Strength, range of motion, and endurance programs can be carried out by using the water to provide assistance or resistance, swimming strokes to encourage limb movements through a desired range of motion, and aerobic activities to promote conditioning. Functional activities, such as ambulation and balance, are facilitated by the buoyancy of the water. Opportunities for socialization and recreation are unlimited and can be recognized through water games and group activities. Submersion in water, particularly warm water, can be very soothing and relaxing. In addition, self-esteem and feelings of well-being may be achieved through carefully designed, goal-oriented programs structured for success.

The Program: Overview

The WETS program was developed and implemented in 1982 at the Jewish Community Center (JCC)-Kaiserman Branch, in Philadelphia. Program participants meet once a week for 45 minutes. The building is accessible by wheelchair, as are the locker rooms, showers, and hair dryers. A private changing area is available for couples. The pool is heated to 86 °F, and entry to the pool is via steps or a Hoyer lift. The program is directed by an occupational therapist, and classes are taught jointly by an occupational therapist and a certified water safety instructor. In addition, the program is staffed by trained assistants—community volunteers, occupational therapy students, lifeguards, and pool personnel—who are trained by the occupational therapist to assist in carrying out individualized programs for the swimmers. The ratio of assistants to swimmers ranges from 1:1 to 1:3 depending on the swimmers' goals and needs. Class size is limited to 12 members with varying diagnoses that cover a wide range of chronic and acute orthopaedic and neurologic disorders. A variety of special equipment is available to the swimmers, including flotation vests, inflated inner tubes, weights, snorkels and masks, and adaptive buoyancy equipment. Flotation devices are used to ensure safety, eliminate fear, achieve a desired position, or facilitate independence (Heckathorn, 1980). Flotation devices allow swimmers to concentrate on propelling themselves through the water without having to devote all of their energy toward keeping their faces above water.

The fee for each 10-week session is $15 for JCC members and $25 for nonmembers. The WETS advisory board, consisting of health professionals; recreational specialists; business, community, and social agency representatives; and disabled consumers and their family members, meets three times a year to discuss present and future concerns. Information...
about the program is usually spread through word of mouth or by local health professionals. A physician's approval is required for registration.

The WETSwim program was developed to enable the adult with physical dysfunction to develop and maintain a level of physical fitness, to continue working toward rehabilitation goals, to resume interrupted leisure and social roles, and to promote self-confidence and independence.

The purpose of the program is to provide opportunities for people with chronic or acute physical dysfunction to take an active role in the management of their physical and psychological status. In an environment where they are able to overcome barriers to participation, they can explore aquatic recreation activities and resume or develop a leisure role. This program affords the opportunity to learn and practice swimming skills, while providing exposure to community resources.

**Individualized Program**

The evaluation I designed to assess each swimmer's functional status in the pool was used to obtain information about Charlie that would be relevant to the program. The initial evaluation revealed that Charlie needed to use the Hoyer lift and be assisted by three people to transfer from his wheelchair into the water. He was unable to stand in the water because he lacked the trunk and hip stability necessary to keep his legs from floating away. He needed assistance for all warm-up exercises (each session begins with 15 minutes of stretching and conditioning activities). With his good natural buoyancy, Charlie was able to float on his back without using a flotation device as long as he was provided with moderate assistance by one person. By abducting and adducting from the shoulder, with elbows thrown into passive extension, Charlie was able to propel himself a crooked 10 feet through the water. We were careful to avoid letting Charlie get overfatigued and, because of his impaired ability to cough and swallow, made sure he did not get water into his mouth.

The interests, values, and program goals of each swimmer are also evaluated prior to designing his or her program. Charlie indicated that his goals for the program were (a) exercises for strength and flexibility, (b) overall conditioning, (c) recreation, and (d) socialization. He was interested in regaining his ability to swim and valued swimming as a method of enhancing his physical performance as well as for leisure enjoyment.

The traditional therapeutic management of the person with ALS includes activities and exercise to maintain range of motion and maximize strength and ADL independence. Gains in strength can frequently be seen in the person with ALS whose muscles are weak from disuse. On the other hand, the continual progression of the disease may make it difficult to recognize gains from a strengthening program. Swimming is felt to be the best general, multisystem conditioning activity for the person with ALS (Zawodniak, 1986). It can be easily graded from a light to a heavy work load because energy expenditure during conditioning is lessened by the buoyancy of the water and because spasticity is reduced in warm water.

An individualized program plan was designed based on Charlie's goals for himself. According to this program Charlie would achieve strengthening and overall conditioning through swimming an adapted backstroke, using available movements. He would meet his recreation and socialization needs by participating in a group program and in occasional games of water volleyball and water basketball. At the time, the rationale was that even if Charlie couldn't play, he would enjoy being in the middle of all the activity. Exercises for flexibility were deleted at Charlie's request because the exercise program he and his wife did at home was sufficient for maintaining range of motion.

Initially, the biggest problem Charlie encountered with the adapted backstroke was that he rolled from side to side as a result of his trunk instability and uneven upper extremity strength (Charlie's right side was stronger than his left). The rolling brought the
Figure 2
A Hoyer Lift Is Used to Lower Program Participant Into the Water

water too close to his mouth and increased the amount of work he needed to do to propel himself through the water. Several flotation devices were tried to help him achieve greater stability while he was swimming and to increase his level of independence in the water, but these devices either did not fit or did not work. An occupational therapy student working with Charlie adapted a flotation vest purchased at Sears by cutting the neck opening to fit Charlie better and by adding lateral supports (made from cut-up kickboards) on either side to eliminate lateral rotation. With the elimination of unnecessary movement and risky lateral rotation, Charlie encountered less resistance and was able to propel himself through the water more efficiently and safely while expending less energy (see Figure 1).

Initially, Charlie’s son came along so that he and his mother could assist Charlie with dressing in the locker room and to help him use the Hoyer lift. After several weeks, Charlie and his wife mastered the art of dressing and undressing Charlie alone, and the staff could put Charlie into the lift without assistance. (For an illustration of the lift, see Figure 2.) Charlie made rapid progress in using the adapted flotation vest, gaining control over the tendency toward lateral rotation, and evening out the force of his upper extremity movements. By the end of his first 10-week session, he was swimming 26 lengths of an Olympic-size pool, with occasional, minimal assistance for direction. He achieved a standing position at pool side with the use of ankle weights. Although for standing he required the maximal assistance of two people (making only a minimal contribution himself), standing provided a much-appreciated opportunity for Charlie to look at the environment from a different perspective. While positioned in an inflated inner tube, Charlie was able to participate in a game of water volleyball and astonished the group with his ability to toss the ball over the net.

Eventually at Charlie’s request, the entire 45-
minute session was devoted to lap-swimming. Surprisingly, at the end of his swim, he showed no evidence of or complained of fatigue as did other swimmers with ALS. In fact, his wife noted that Charlie was able to provide more assistance during wheelchair-to-stand transfers after swimming than at other times during the week. Both Charlie and his wife reported that his energy level remained higher for several days following the swimming sessions, enabling him to participate in and enjoy more activities. They also observed that during the summer and winter vacations, when classes were suspended, Charlie's energy level was noticeably reduced and that he seemed to be in better condition during the months that the WETSwim program was in session. Although there is no quantifiable evidence to support an explanation for the fluctuations in Charlie's energy level as a result of his participation in the WETSwim program, it could be surmised that the physical exercise produced a positive effect, both physically and psychologically.

Value of WETSwim

The model of human occupation (Kielhofner, 1985) is central to the WETSwim program. The activities are performance oriented, yet each swimmer's program is designed to place control in the hands of the swimmer. The program's high degree of flexibility promotes a variety of roles and values. It is possible to gradate and adapt most aquatic activities, and levels of socialization and interaction are flexible. With an educational background that includes a knowledge of illness and pathology, sensitivity to the psychosocial aspects of health and illness, and the skills to promote functional movement in the light of a swimmer's disability, the occupational therapist is uniquely qualified to run programs like WETSwim.

In this era of increased awareness of and attention to physical fitness, people experiencing physical dysfunction are not willing to be excluded. Because many physical activities are unavailable to this disabled population, an aquatic program can provide the person with ALS with a realistic alternative for maintaining physical fitness, continuing with rehabilitation goals, and participating in an affordable leisure activity. These programs can also provide participants opportunities to explore and master aquatic skills in an activity and environment where physical limitations are less apparent. Persons with chronic, degenerative illnesses, who may be experiencing physical deterioration on a regular basis, can see themselves improve in the functional areas of swimming skills and independence in the water.

The buoyancy of the body in water can make it easier for participants to make many movements which are otherwise hampered by gravity, including ambulation. Aquatic activity also facilitates the use of muscles that are not frequently used during regular daily activities and can give overused muscles a rest (an important consideration for people with post-polio syndrome). A person's fear of falling isn't nearly as great in the water as it is on land. Water provides a medium in which the swimmer can explore the use of his or her affected extremities in activities not possible on land (i.e., walking without a cane, playing volleyball). Relaxation techniques can be successfully taught and carried out in the water, and warm water can have a relaxing effect on tight or spastic muscles.

For many participants, simply being involved in the program has had special meaning. It becomes something to look forward to each week. The program provides participants with a chance to do something for themselves, something uniquely their own, without the assistance (or interference) of their families. The program offers a chance to get out of the house and experience a positive social interaction with others in an environment where the focus is on ability. Swimming can reduce self-consciousness because disabling conditions are often less apparent in the water, and limitations are lessened. For those with communication disorders, swimming affords the opportunity to participate successfully in an activity that does not require verbal interaction. Water safety skills can be carried over to other settings and could be valuable to those clients who are interested in fishing or boating. Aquatic programs can be designed to meet a wide variety of therapeutic goals, limited only by the creativity of the therapist. One can find applications for visual and auditory discrimination, creativity and self-expression, eye-hand coordination, following directions, sequential thinking, spatial awareness, kinesthetic awareness, and body awareness (Priest, 1976). Above all, these programs offer opportunities for competition, independent self-fulfillment, and fun.

Summary

The opportunity to participate in wellness programming can be particularly valuable to persons who must be prepared to deal with continuing gradual physical deterioration for the rest of their lives. During time periods when his health was stable, without evidence of a rapid progression of the illness, Charlie was able to devote some energy to the pursuit of swimming, an activity he had enjoyed for many years. The WETSwim program provided the opportunity for Charlie to take an active role in the management of his physical and psychological status. In an environment where he was able to overcome barriers to participation, Charlie could explore aquatic recreation activities and resume a leisure role. He experienced the
opportunity to learn and practice swimming skills, develop an area of performance to a mastery level, and improve his quality of life.

Occupational therapists are no longer confined to the traditional locations for and methods of providing treatment. Encouraged by the changing economics of health care, they seek alternative ways of providing quality health care (Frazian, 1985). Persons with short-term physical dysfunction, as modern consumers, are taking greater initiative in the medical management of their dysfunction and seek alternatives to passive forms of treatment. Persons with chronic or long-term physical disabilities, in addition to having basic needs for optimal sensory-motor function and ADL independence, are becoming increasingly interested in physical fitness. The WETSwim program offers a wide range of opportunities, medical and recreational, functional and social, to the consumer with physical dysfunctions.

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References


