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**Aquatic Rehabilitation
for Medically Fragile and
Terminally Ill Children:
A Case Study**

**Effects of Water Exercise
on Muscle Strength
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**Aquatic Rehabilitation
For Orthopedic Trauma:
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Aquatic Rehabilitation for Medically Fragile and Terminally Ill Children: A Case Study

The decision to bring into a pool a medically fragile child or a child having a life threatening illness requires careful consideration. Parents need to be enthusiastic and dedicated to the values of aquatic activity. Pool management must cooperate in the endeavor. Aquatic specialists accepting medically fragile and/or terminally ill children into their practices need to be highly skilled, aware of disease progression, and able to adapt handling skills to the child's specific needs.

The goal of aquatic therapy for medically fragile children and/or children with life threatening illness is to, as much as possible maintain and improve quality of life. For some children this means providing palliative care. For other children this becomes end of life care.

The Decision to Proceed with Aquatic Rehabilitation

Warm water aquatic therapy can play a vital role in habilitation/rehabilitation of children with cerebral palsy, sensory processing disorders, arthritis, spina bifida, cancer, Down syndrome, orthopedic disorders, rare diseases such as Tay-Sachs and Niemann-Pick, as well as other syndromes where motion and breathing need improved synchrony.

Children who have diseases severely limiting activities of daily living often can benefit the most from aquatic rehabilitation. These children, however, are the most challenging cases. Recently, there has been an increased effort for improving palliative and end of life care to our rapidly aging elderly population. In the United States, however, very few facilities and practitioners, skilled at providing care for children and their families as they confront life-threatening illness, exist. The Initiative for Pediatric Palliative Care (IPPC, 2004) has outlined three segments of the pediatric population who would

benefit from enhanced palliative care services:

- those who are born without an expectation of survival to adulthood but who live a long time with substantial suffering,
- those who acquire illnesses such as cancer, and
- those who suffer a relatively sudden death due to trauma.

A great deal of preparation and planning is needed before the child enters the water. Following is a case study of a child with Niemann-Pick Disease, Type A (NPA) illustrating how close cooperation and collaboration among parents, practitioners, service agencies, and pool management can lead to a positive delivery of pediatric palliative care in the aquatic environment.

CASE STUDY: AQUATIC THERAPY FOR A CHILD WITH NIEMANN-PICK DISEASE TYPE A

Children with lysosomal storage disorders, such as Niemann-Pick Disease Type A (NPA), are born without the expectation of a life expectancy beyond a few years. Children born with NPA are missing the enzyme acid sphingomyelinase (ASM), responsible for metabolizing and breaking down sphingomyelin, a special lipid component of cell membranes. If ASM is absent or not functioning properly, sphingomyelin abnormally builds up, leaving fatty deposits called "foam cells" in many body tissues and organs, primarily the brain, liver, spleen, lungs, and bone marrow. The sphingomyelin pairs with cholesterol and leaves the affected organ with a swollen, foamy appearance (Bank, 2002).

Impact of this enzyme deficiency is enormous on the central nervous system, resulting in progressive neurological impairment, profound developmental delay, progressive spasticity, epilepsy,

enlarged liver/spleen, and a characteristic "cherry" red spot in the eye. Children with NPA exhibit a variety of symptoms including muscular weakness manifested by feeding difficulties, loss of early motor skills, abdominal distention, hepatosplenomegaly, hypotonia, hypersensitivity and skin with a yellowish brownish discoloration. Death usually occurs between 2-4 years of age.

Baby Sophia

In summer, 2002, we began caring for Baby Sophia in the aquatic environment. She was 14 months of age. Our aquatic program was initiated as part of Sophia's Circle of Healing, a holistic model of care her parents had developed to increase the quality of Sophia's life and search for a cure for NPA. At this time, Sophia required the assistance of one aquatic practitioner. Despite her small size, she demonstrated good head support. Sophia was flexible and able to perform supported kicking on her back. She was also able to support herself in an inner tube for a few minutes and her arm movements resembled a dog paddle. We were careful to keep her ears out of the water. The maximum endurance she had for an aquatic session was 25 minutes.

At 16 months, Sophia began losing weight, her tactile sensitivity increased, and her tolerance for environmental noise in the pool environment decreased. However, Sophia was still able to achieve assisted flexion and extension of her legs in the water. By fall 2002, Sophia had frequent respiratory and fungal infections and was in neurological decline. In February 2002, two choking and apenic episodes led to a hospitalization and her return home on hospice. As a result, we temporarily suspended aquatic therapy through winter 2003.

attendance is a clear indicator of the positive impact that aquatic rehabilitation has had on this child with NPA.

Programming Implications

When a parent approaches aquatic facility staff about the possibility of aquatic therapy for their child with a life threatening illness, they frequently face resistance since there are real risks to be addressed. Children with severe, progressive, life threatening illnesses often present with what most would call "contraindications" to pool therapy—nasal gastric tubes, supplemental oxygen, seizures, urinary and bowel incontinence and high susceptibility to infection. Moreover, pool management may be concerned about scheduling, whether their facility is appropriate, issues of liability, cost of providing labor intensive care, and the impact providing care will have on other pool clients.

The first barrier to consider is appropriateness of the pool environment and trained staff. Medically fragile children can be hypersensitive to sound, touch, water temperature, and water turbulence. So precision in pool scheduling will take cooperation between all staff members, as well as pool clients. How a child enters/exits the pool is another consideration. Ideally, the pool would be equipped with a pool ramp for easy wheel chair access. If the child is very small or has no postural control, he or she will need to be carried, which requires staff strength and skill. A parent or caregiver can be trained to assist. Appropriate aquatic clothing needs to be discussed. Warm water clothing made of Neoprene can be custom made to maintain thermoregulation.

A child who has bowel/urinary incontinence should be double diapered with rubber pants over the diaper. Skilled aquatic practitioners with advanced handling skills should be able to palpate the abdomen, and monitor for changes that could indicate incontinence, being prepared to quickly evacuate the child if necessary. An additional precaution that can be taken to address incontinence is to coordinate the child's pool time around feedings and usual bowel movements.

If a child requires an indwelling nasal gastric tube or supplemental oxygen, 2 aquatic practitioners are needed — one to carry the child and another responsible for making sure the tubing is not obstructed. A nasal gastric tube should be disconnected from the feeding source prior to pool entry. The exposed end can be covered with plastic wrap to prevent water contamination.

Oxygen usually needs to be continued while in the pool. Children who require nasal gastric and oxygen tubing entail more risk, but with the appropriate length of tubing and an assistant responsible for the tubing, these risks can be managed and passive horizontal aquatic modalities can be performed on the child.

If a child has a tendency to experience seizures, close communication with parent and physician can help aquatic practitioners distinguish between seizing activity that is serious or mild, in order to decide whether to continue the aquatic session or seek medical attention.

If a child is highly susceptible to infection due to a compromised immune system, careful attention to the pool facility environment is required. Outside the water, parents should pay careful attention to where they dress and change the child. Since mold, mildew, and fungus thrive in the humid environment of indoor pools, to minimize exposure to these organisms, parents should bring their own towels and sheets to cover the changing table.

Pool chemicals should be checked prior to the session and if chlorine or bromine levels are low, the child's aquatic session should be rescheduled. If the pool water is cloudy, most likely the chemicals and filtration are out of sync and parents should be wary to allow their child in the pool.

With careful planning, many so called contraindications to pool therapy can be addressed. This labor-intensive work is costly and, ideally, public and private funding could subsidize pediatric aquatic rehabilitation sessions in order to diminish access barriers. Absolute contraindications to aquatic therapy, however, do exist and these include

active infections, diarrhea, fever, and recent persistent seizure activity.

Impact on Pool Staff and Clients

When we first brought Sophia into our facility for aquatic therapy, there were some challenges. Of prime importance was finding a time when Sophia would be awake, fed, diapered, and ready for activity. She needed a quiet protected space away from the commotion caused by our ambulatory clients. We decided on an 11:30 am timeslot since this was after our adapted aquatics program and before our senior swim at noon. This posed a slight delay for individuals in our senior program. However, the mother and nursing staff educated the pool clients on Sophia's fragile health and this has promoted more cooperation and consideration of pediatric rehabilitative needs in a pool environment now dominated by therapeutic rehabilitation of our local elderly population.

Many pool staff were concerned whether Sophia would actually benefit from aquatic rehabilitation. Staff who shared the pool during our session with Sophia quickly learned to work around us. Our pool colleagues limit movement to keep splashing and water turbulence to an absolute minimum. Eventually, other staff members learned to work with Sophia, and this opportunity enhanced staff training and fulfillment.

PALLIATIVE CARE VERSUS END OF LIFE CARE

When dealing with children having terminal illness, issues of liability are of special concern to pool management. Aquatic therapy, by its very nature, is relaxing and diminishes pain. By providing comfort care, palliative care seeks to prevent or relieve physical and emotional distress produced by chronic, life limiting or terminal illness. Pediatric palliative care helps a child and his or her family live as normally as possible, for as long as possible, by preserving the dignity and integrity of both the pediatric patient and his or her family.

It is important to note palliative care is NOT limited to people thought to be

dying. Palliative care can be provided concurrently with life-prolonging treatments (Institute of Medicine, 2003). For Sophia, we are providing palliative care in the aquatic environments, care that specifically addresses pain management, assistance in breathing and bowel functioning, and progressive muscle relaxation. We try to improve her quality of life by making her feel better, while her parents pursue potentially life saving experimental treatments.

As the child's medical condition fluctuates, however, the distinction between palliative care and end-of-life care is not always clear. End-of-life care focuses on measures preparing for an anticipated death and in the warm water aquatic environment that usually means reducing pain. Those involved with pediatric hospice care understand death often finally occurs when a child is able "to let go" of pain. So there is a remote possibility passive, horizontal aquatic modalities that relieve pain and facilitate muscle relaxation can facilitate the dying process in children with life threatening illness. Although aquatic practitioners may want to relieve pain and suffering, while providing palliative care, it is not advisable to have the child pass away in most pool facilities.

In the United States, most pools have parents sign a detailed waiver of liability directly addressing these issues, releasing both the aquatic practitioners and the facility from legal prosecution if death occurs in the aquatic setting. It is important to note, however, the first pediatric hospice in the United States, the George Mark Children's House (www.georgemark.org), recently opened in San Leandro, California. This facility does provide aquatic therapy to children in their final days of life. Since the staff at this center has extensive training in hospice caregiving, issues of liability are of less concern to aquatic staff in this environment. Parents who wish to have aquatic therapy sessions for their child in the end stages of life should seek out these hospice facilities with warm water therapy pools.

Conclusions

Bringing a medically fragile child into the pool environment requires a great



deal of effort and coordination. Providing pediatric palliative care in the aquatic environment is possible and is

not only a worthwhile endeavor, but a medically beneficial, morally justified, community building enterprise, and an important opportunity for staff learning. It is our hope this case study will inspire other practitioners to provide aquatic therapy for children with life threatening illness.

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Kathryn Azevedo, Ph.D., ATRIC, is a clinical researcher at Stanford University Medical Center where she runs clinical trials. In her 20 years in aquatics, Dr. Azevedo has attained numerous aquatic and massage certifications and is a Master Trainer for the Arthritis Foundation. She began her aquatic career as a volunteer in the community based aquatics program designed by the late Betty Wright. In graduate school, she worked with Project PROJIMO a rural community based rehabilitation center for children in Sinaloa, Mexico. She wrote her master's thesis on community-based rehabilitation and helped to edit the newer editions of "Where There is No Doctor" and "Disabled Village Children". While at C.A.R., Dr. Azevedo won an Arthritis Community Grant to test a pilot pediatric arthritis program and developed assessment and training materials for their former adapted aquatics program. She now works with the Special Needs Aquatics Program (SNAP) as they seek to expand community based aquatics programs for children with special needs throughout the San Francisco Bay Area.



Vladimir Choubabko
West Valley College,
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Vladimir Choubabko has achieved a broad base of expertise in his 40+ years in the aquatics field. In Russia, he graduated from the prestigious Institute of Physical Education and Sport with a degree in physical education, physical therapy, massage, and coaching. As a coach in Olympic swimming, he produced outstanding results in coaching 9 Olympic gold medalists. He is well known for his dedication towards his athletes and was also able to inspire hard work and commitment from his coaching staff. This success propelled him to the national level of sports administration in the former Soviet Union where he managed a budget of several million dollars. From 1980 to 1988 he was responsible for training, organizing, and budgeting Russian Olympic swimmers. Vladimir was awarded several medals of excellence for this work. In the United States he has continued his education in aquatics and geriatric physical education. Vladimir now works as a lead physical education instructor at both West Valley College and Mission College. At C.A.R., he is the lead aquatic personal trainer and massage therapist.



Karen Herzog
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Karen Herzog is the mother of Sophia Sachs, who is battling Niemann-Pick Disease, Type A (NPA). As an educator and advocate for children's health, Ms. Herzog is a founding advisory board member of the UCSF-Stanford Jewish

Genetic Disease Center. Out of what she learned from Sophia's struggle for survival and her family's search for meaning in the midst of uncertainty, she created *Healing in Community*, a compassionate and highly effective community-based approach to caring for children with life-threatening conditions and their families. She co-founded Sophia's Garden Foundation to share this knowledge with the world.

Reviewer Comments

Julie Meno Fettig

This article brings awareness of the role aquatic therapy can play in management of pain and providing palliative care. Sophia's case study is an excellent example of how coordinated professional disciplines, different services, and timing of treatment need to be for successful aquatic therapy with a medically fragile child. Warm water aquatic therapy is an excellent pain management modality. Aquatic therapy for the treatment of pain has greatest benefit when water is clean, temperature correct for patients condition, and environment is calm. The therapist should be knowledgeable about the specific condition, adaptable, reassuring, empathetic, yet humorous. This three dimensional supporting environment can be a great equalizer against pain. When suspended in water, without fear, it allows us to feel and sense ourselves from within. From within we can heal ourselves, feel strong, in control, and very much alive. ♦

Reviewer Bios

Julie Meno Fettig, CTRS, ATRIC, is the founder/owner of Therapeutic Aquatics, Inc. and aquaticcentral.com, specializing in consulting, information, and rehabilitation. She is the author and publisher of *The Bad Ragaz Ring Method Visual Instructional Manual* and video and co-producer of the *PNF in the Pool* video. She received the 2002 ATRI Tsunami Spirit Award. ♦

Feature Column: Pool Problems

Cloudy Pool Water

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Aquatic professionals often notice that pool water becomes turbid gradually throughout the day or immediately after lengthy periods of peak use. Cloudy water conditions may also occur immediately after chemical adjustments are made. Water may appear cloudy or milky. A fine white precipitate may settle out of the water. Water clarity frequently deteriorates to the point where it is not safe to continue operation and classes or programs must be cancelled.

Although water clarity should exceed 0.25 NTUs (Nephelometric Turbidity Units), most public pool bathing codes permit swimming pools to be used until the clarity deteriorates to the point that either the main drains or a 6-inch diameter black disk can't be clearly seen from the surrounding deck at the deepest point in the pool, or the black and red (or black and white) quarter panels on a 2-inch diameter, Secchi disk cannot be distinguished at a depth of 15 feet.

Aquatic professionals should insist water clarity be maintained within an acceptable range. It should be understood that activities will be cancelled rather than endangering users. Written pool rental agreements should outline how the instructor or therapists will be compensated for lost fees or wages if the pool is not able to be used. If cloudy water problems result in more than very infrequent pool closures, the cause of the problem should be identified and remedied.

Water clarity problems can usually be traced to one of two possible causes – either physical or chemical in nature. Physical problems are caused by the design of the circulation system or mis sized equipment. Chemical problems usually result from improper application of chemicals, incorrect dosing, or from not correcting water quality problems when they occur.

Chemical Problems

Sometimes chemicals are added to water in too great a quantity in too short a period of time. With the exception of chlorine, pool chemicals should be added to the pool gradually, and in small quantities over an extended period of time. Pre dissolve solid, granulated or powdered chemicals prior to their addition. Try to limit chemical additions to 10 ppm changes at a time.

Excessively high Total Dissolved Solids (TDS) can cause water to appear less than crystal clear. Use a TDS meter to determine the level of total dissolved solids. In pools with high bather load to water volume ratios, regular dilution is recommended at a rate of 8 gallons per pool user per day. If TDS levels exceed 1,500 ppm and are causing problems with taste, clarity, ability to maintain ORP levels, or galvanic corrosion, dilute significantly, or drain and refill the pool with fresh water.

High concentrations of cyanuric acid will interfere with oxidation of organic contaminants in the water. Do not use cyanuric acid or chlorinated isocyanurates, such as trichloro-s-triazinetrione or sodium dichloro-s-triazinetrione, in indoor pools, or in outdoor pools and spas with extremely high organic loading problems. If cyanurates are used to prevent loss of chlorine and dissipation into the air due to exposure to ultraviolet light, use them in moderation. Keep cyanuric acid levels in the 10 ppm – 20 ppm range since 95% of the staying power benefit is achieved in that range. Also, the negative effects on pathogenic organism kill time and depression of ORP are still within an acceptable range.