Integrative and Complementary Therapies—Part Two ISSUE #56 | AUGUST 2019



Pediatric E-Journal

PEDIATRIC ADVISORY COUNCIL Released in collaboration with the National Hospice and Palliative Care Organization



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Issue Topic: Integrative and Complementary Therapies-Part Two

Welcome to the 56th issue of our Pediatric e-Journal. This issue explores some of the many different types of integrative and complementary therapies that can contribute to the care provided to children, adolescents, and family members as part of the overall services offered by programs of pediatric palliative or hospice care. As indicated in the introduction to Issue #55, we were pleased and a bit surprised to realize how widespread the interest in these topics was as we prepared these two issues. In total, we received more than 20 contributions, a much larger number of articles than we have ever received for a single issue. Clearly, integrative and complementary therapies are becoming of increasing importance in pediatric palliative and hospice care, and practitioners of those therapies are ever more eager to describe their roles in these types of care.

We do not wish to complain about receiving an unexpectedly large number of contributions to this subject, but it is important that many good articles not be overwhelmed or lost in a single grouping of such articles. As a result, and as explained in the introduction to Issue #55, the Pediatric e-Journal Workgroup decided to allot two issues on this subject, of which this is the second.

In the past, we had occasionally split issues on a single topic area into two parts in this way, but more recently our desire was not to do so in order to be able to cover a broader range of subjects in a single year in our four quarterly issues. So, the present division into two issues is a one-time response to an unexpected but gratifying abundance of riches.

Even so, we appreciate that the many articles in this and the preceding issue can still only cover a limited number of examples of integrative or complementary therapies. It is our hope that these two issues can spark discussion of an even larger number of ways to include similar therapies in pediatric palliative and hospice care. In any event, our goal is to provide at least a beginning in discussing such matters.



This e-Journal is produced by the Pediatric e-Journal Workgroup, a subgroup of the National Hospice and Palliative Care Organization's Pediatric Advisory Council. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Ann Fitzsimons. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as Myth Busting for a future issue in 2019 and we are open to consider topics for our four issues in 2020. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at ctorkildson@mail.cho.org or Ann at ann@here4U.net

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Issue #56: Integrative and Complementary Therapies—Part Two Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.

Massage Improv

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Marcia Degelman, CMT Marcia contributed an article on pediatric massage to Issue #55. Here she offers a poem describing the work of a therapist and the need for taking good care of one's self.

Stories from the Front Lines: How Integrative Medicine Has Allowed Me to Better Care for My Child with Medical Complexities p. 8

Dannell Shu, BFA, MWS

In this article, Levi's mother shares "three specific stories about the use and value of Integrative Therapies for my son, Levi, a child born with severe brain damage. Each story is an example of



how when the worlds of Western Medicine and Integrative Therapies are made available to families, children receive better care, symptom management, and improved quality of life. This in turn benefits the whole family." The author is careful to note that, "Every tool has its purpose and limitation. As a parent of a child with medical complexities, one of my responsibilities is to build a robust toolbox to support the variables of my child's medical, physical, social, emotional, relational, educational, and spiritual needs." Her toolbox includes traditional therapies, alone or in combination with each other, as well as integrative therapies of many types and from many different sources.

Reiki in a Pediatric Palliative/Hospice Setting

Benedicte Thymann Nielsen, Marcus's Mother

When Marcus was 8 years old, he was diagnosed with an aggressive form of leukemia. **Tragically, during treatment** "he suffered devastating neurological side effects and ultimately became comatose. MRIs revealed he had global and irreversible brain damages and that he would never recover." Seeking ways to help him, a palliative oncologist recommend that his parents try reiki. Here, his mother explains this form of therapy, how it was applied to Marcus, and her efforts to qualify as his therapist. She concludes: "Knowing that I did all these wonderful things for him made his last months less painful for me. I gave Marcus his last healing a few hours before he died. He was in a beautiful and peaceful place surrounded by love."

Integrating Gentle Movement Exercises in Pediatric Palliative Care

Stephanie Parry, MD, BSPH, Beth Staenberg, MA, OTR/L, 300-hour RYT, and Meaghann S. Weaver, MD, MPH, FAAP

Drawing on an electronic literature search, this article offers "suggestions for integrating gentle movement exercises including Tai Chi, Yoga, and Qi Gong into the care of children with complex conditions and their caregivers in the context of pediatric palliative care." Lessons learned include "the mutual benefit to patients and family caregivers; the symptom support provided through gentle movement offerings; the subjective experience of well-being; and the ready feasibility of implementing gentle movement as part of care."

Shonishin/Non-Invasive Acupuncture as a Non-Pharmacologic Approach in Pediatric Pain Management

Robyn "Ra" Adcock, LAc

This article describes a "specialized form of non-invasive pediatric acupuncture [that] hails from 17th century Japan and is called Shonishin." This therapeutic technique "does not use regular acupuncture needles that are inserted into the body. Instead, it uses a variety of handheld tools that are designed to treat the surface of the skin with very gentle, rhythmic tapping, rubbing, pressing, scratching or scraping techniques." As the author explains, "Shonishin rarely targets specific acupuncture points, which are located at precise anatomical landmarks, but rather focuses techniques in specific stroking directions over general regions of the body." As well, "Shonishin employs the body's largest sensory organ, the skin, to communicate with babies and children."

Music Therapy and Yoga: Stretching the Limits of Care

Jessica Sturgeon, MT-BC, HPMT

"This article explores how music and yoga were combined to provide comfort to pediatric patients with life-limiting and terminal illnesses to address both physical and emotional goals." By combining these modalities, "we saw that many of our pediatric patients were observed with and reporting increased relaxation, confidence, and emotional regulation and coping. In addition, there were reports of less anxiety, better/easier movement, and decreased pain when repositioning or during physical therapy and occupational therapy sessions. The use of yoga was



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able to have more success as the music created a safe and relaxing space through live, responsive music, play, and rapport." Two extended case studies illustrate this therapeutic combination.

Music-Thanatology for Pediatric Patients

program does not employ a music-thanatologist.

Tony Pederson, CM-Th, and Margaret Pasquesi, MA, CM-Th According to these authors, Music-Thanatology "is a palliative modality, which uses live music on harp and voice to alleviate pain and suffering at the end of life. Music-thanatologists...bring this individually tailored music to the bedside when death approaches—when patterns are shifting, and body systems are failing." The article explains the context in which music-thanatology is used and the details of its practice. To this, the authors add an extended case example to illustrate these points and offer suggestions as to what a hospital or hospice can do if their

Art Therapy at Camp Kangaroo

Teresa J. Sit, MAAT, LPC

Art therapy is another well-known complementary therapy. Here its role is explained as it has been employed in an annual bereavement camp. A vivid figure illustrates one art-making project. As the author writes, "Art allows the individual to make abstract thoughts and concepts tangible, visible. The process of art making can clear the mind of distractions, allowing a story to take shape, giving form to memory. It allows us to give shape to our own individual culture and to share our culture with those around us—to say to someone, 'this is how I feel loss, sadness, anger' and to seek camaraderie. Art making provides us with a useful coping tool, a way to bridge connections with others, and a way to integrate past experiences into present-day living. In this way, creative arts interventions used during bereavement camps provide children and adolescent participants with a toolbox for grieving, honoring emotions, and moving forward."

Clinical Hypnosis and Hypnotic Language in Pediatric Palliative Care

Lawrence J. Fenton, MD

Here is an account of hypnosis by an experienced physician who writes, "I have now taught selfhypnosis to over 150 patients, approximately two-thirds of which were children, ranging in age from 5 to late teens. The predominant symptom prompting referral was pain, both acute and chronic. Anxiety and insomnia are also common and often part of the pain syndrome. Nausea, vomiting, habits, and tics made up most of the rest. I am not a counselor, so I seldom see patients with complex psychological issues underlying their pain unless it is in conjunction with a counselor." He explains, "I don't wish to imply that these techniques are successful in every situation and with every patient. They are not. However, the risk-to-benefit ratio is negligible and the success rate extremely high," leading to the conclusion that "Clinical hypnosis is an evidence-based, highly-effective tool that can be used to treat common symptoms encountered in the practice of palliative care."

Pediatric Massage: A Gentle Approach for Pediatric Palliative Care

Tina Allen, LMT, CPMMT, CPMT

"For children and families living with and managing serious illness," this article maintains that "pediatric massage is an essential and necessary component to provide comfort and quality of life." The author argues on behalf of the need for positive touch, advocates a family-centered approach, insists that choices matter in delivering this type of care, and outlines specific approaches and considerations in employing massage for pediatric pain relief.



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Joy and Laughter: Pet Therapy in Pediatric Palliative Care

Christy Torkildson, RN, PHN, PhD, FPCN

This article describes the author's work with a trained service dog—a two-year old golden retriever—at a major children's hospital in Oakland, California. Based in the hospital's complex pain and palliative care program, Sundance offers his own special support services to patients and family members, as well as to clinical and support staff throughout the institution. The article concludes: "In an informal survey of staff, it was clear that any reservations about having a dog in the hospital and interacting with our patients were far outweighed by the benefits they have witnessed, with most requesting the addition of more dogs. For me, it has been humbling and an honor; Sundance has brought joy and laughter to all of us."

ADDITIONAL NOTES

The Pediatric Advisory Council is a council of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, Pediatric Advisory Council and its E-Journal Workgroup, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this e-Journal from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and "opt-in" for communications from Pediatrics. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the Pediatric Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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Massage Improv Marcia Degelman, CMT



photo by: Julianna Degelman

taking folks on a guided tour Each one unique Each session a new voyage

Following sinews, bones, the tendons, muscles, and joints Ancient injuries, Modern tensions.

The spine a winding road, nerves branching out like limbs of a tree. skin communicating with brain and gut, Pain appearing and disappearing, constant as the northern star for some Gentle rocking, helping them clear the pain

The tide of blood and lymph, the subtle pulsing of cerebrospinal fluid, fascia twisting and turning

follow the energy

tracing the meridians and spinning chakras



All different maps of the same terrain of body, organizing reality according to chi or prana or life force the natural course, respecting the bodies' miraculous ability to heal.

Listen with your fingertips, more than you talk. Listen to the body helping unravel the stress; switch to parasympathetic away from fight or flight into rest and digest. change brain waves from beta to theta entrancing deep relaxation...

connect with each person acknowledge the parent ask permission respect boundaries

listen to your own body- go to sleep when you're tired find fun ways of moving dancing, swimming, stretching and resting on the floor, swinging arms walking in sunshine

nourish yourself to be able to come to this work glad every day.

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Stories from the Front Lines: How Integrative Medicine Has Allowed me to Better Care for my Child with Medical Complexities

Dannell Shu, BFA, MWS Parent Advocate & Educator: Palliative & Hospice Care Member of the MN Palliative Care Advisory Council Dannell@MamaShu.org

A child with medical complexities greatly depends upon the world of Western Medicine, including its medical specialists, tools, strategies, innovations, therapies, equipment, and pharmaceuticals. The more nuanced or rare the complexities, the deeper into this incredible world the child and family lives. With all of the advancements available through Western Medicine, why would a family pursue Integrative Therapies, particularly for the most medically complex child?

In this article I share three specific stories about the use and value of Integrative Therapies for my son, Levi, a child born with severe brain damage. Each story is an example of how when the worlds of Western Medicine and Integrative Therapies are made available to families, children receive better care, symptom management, and improved quality of life. This in turn benefits the whole family.

A Robust Toolbox Matters

Every tool has its purpose and limitation. As a parent of a child with medical complexities, one of my responsibilities is to build a robust toolbox to support the variables of my child's medical, physical, social, emotional, relational, educational, and spiritual needs. Tools range from objects (equipment/pharmaceuticals), to people (providers), to strategies (when/how to use), to therapies (PT, feeding), to procedures (tests, surgeries), and so forth. The longer my child is alive the more we experience the limitations of a tool and the unique factors that impact my child's medical complexities. These are some of the many reasons why we pursued the expansion of my son's toolbox to include multiple aspects of Integrative Medicine (20+ modalities). Here is a story that illustrates why having a robust toolbox matters.

Without warning or evident cause, a series of red-hot welts appeared one morning on my son Levi's skin. It was evident even a feather-light touch upon them caused him significant pain. We monitored them, tracking all the variables that could help us discern what was happening. In a scheduled clinic visit that afternoon with his palliative care physician, it was determined the cause was likely viral. We had the option of giving him Tylenol for the pain, but the only remedy for the virus was to just wait it out. There was no telling how long the virus could linger, the best estimation was 7-10 days.

Given Levi is a child with significant medical complexities, we are thoughtful about every medical decision we make on his behalf. Our preference as parents isn't to default to pharmaceuticals because even the smallest side effect can ripple in unfavorable ways. As a result, we established a relationship with a Naturopathic Doctor whose experience includes Chinese medicine, Native American medicine, homeopathy, local herbal remedies and acupuncture.

Right after our palliative care clinic visit, I reached out to our Naturopathic Doctor for his input. After hearing the full story, including our clinic visit results, his assessment was that Levi's virus was trying to leave his body via his skin (very common) and we could



easily assist this process. He recommended we stop by his clinic on the way home, pick up a dried leaf, add in clippings from the cedar bush in our front yard, and make a tea. We were to then soak a washcloth in the cooled tea and place it upon Levi's red welts anytime we saw them surface. This "tea" would draw out the heat in the welts which would eliminate pain while also drawing out the virus from his body. We decided to skip the Tylenol and go with the tea. The effectiveness was astounding. The tea did exactly as the Naturopathic Doctor described and within 24 hours the virus was 90% gone. The 10% lingered one more day, during which the welts were diminished in color, size, frequency, location, and without pain.

A year later similar viral welts appeared on Levi. This time we had the "tools" and strategy readily at hand and were able to respond within minutes. Not a single dose of Tylenol was needed and the virus lasted less than 24 hours in all. As a family, this gave us back a week of life that otherwise would have been spent at home managing the stress of Levi being sick and the virus symptoms.

When Traditional Therapies Aren't Enough

In our home, we define Traditional Therapies as those paid for by insurance, specifically Medicare. Generally speaking, these include the fields of PT, OT, speech, hearing, vision, feeding, and sometimes chiropractic. Generally speaking, these therapies focus on improving the functionality of the body or body-brain connections, but they do not focus on neurological development or "growing the brain," rather they focus in training the brain how to work within its limitations.

For children with medical complexities, Traditional Therapies are important and critical resources to have within a child's toolbox. These therapies can be a doorway toward greater functionality. There are also a lot of situations for children with complexities where Traditional Therapies alone (or in combination with each other) aren't enough. Additional approaches are needed, in combination with Traditional Therapies, to develop their neurology. This gives a child greater access to themselves, the people, and world around them. Here is a part of our story where this combination was most impactful.

By 20 months of age my son Levi had been receiving homebound Early Intervention services through our local public-school district for 17 months. Having been born with severe brain damage and medical complexities, it was amazing he was still alive at 20 months, let alone able to make minimal progress through Traditional Therapies. His education team included PT, OT, Vision, an Audiologist, and a Special Education teacher. They were each veterans in their field who offered Levi the best of their profession. We were fortunate not to have to deal with common barriers in special education like disbelief in my child's potential, unwillingness to offer him the full scope of educational resources, or restrictive budgets and schedules.

Even with all of these factors, my son's progress was very limited, and it was unclear if this was a result of his brain damage or the scope of the therapies themselves. Like any parents desiring the best for their child, we began to explore additional approaches for helping Levi grow and develop. We were looking for something that supported our values and was non-invasive. It was in this season we discovered Hyperbaric Oxygen Therapy (HBOT) which impacts brain activity and development through increasing oxygen and blood flow supply to the brain. After lengthy conversations about the pros/cons of HBOT with our palliative care team, various HBOT providers, and families whose children had



completed HBOT, we decided to take the risk of traveling out of state to a clinic specializing in HBOT for children with medical complexities. It was a "risk" in regards to if the therapy would be effective for my son, not in regards to side effects or putting his life in jeopardy. Medically speaking HBOT is non-invasive.

Given Levi's diagnosis, he was prescribed a series of 40 HBOT sessions over the course of two months. Before the halfway point, measurable progress was made in his vision, gross motor movement, fine motor movement, vocalizations, and response times—the very things his Early Intervention school therapies were working on. This progress continued through the 40th session.

While at the HBOT clinic we learned of a neuro-sensory-reflex therapy that could build upon the neurological growth from HBOT and further develop Levi's abilities. We met with a specialist to complete an assessment and took home an extensive home program of therapies. Over the coming year we completed these therapies daily while also continuing with Levi's Early Intervention school specialists.

The combined impact of these Traditional Therapies and Integrative Medicine modalities was life changing for my son and our family. His vision, hearing, gross motor, fine motor, expressive communication, response times, engagement with people and the world around him all significantly improved. So much so that two years later Levi completed a second round of HBOT treatment and expanded his neurotherapy to include Masgutova Neurosensorimotor Reflex Integration (MNRI) therapy. This combination lead to even greater improvements as he accomplished things previously thought to be impossible for him including standing, walking, solo and interactive play, plus significantly reduced spasticity (within his cerebral palsy diagnosis), and shortened response times.

At the age of 3 Levi experienced an apneic event that robbed him of nearly all of his progress. It was heartbreaking. Traditional Therapies alone did not have more they could offer Levi, other than to start from the beginning of the process. MNRI offered Levi an eight-day intensive program followed by twice weekly sessions with a provider and a detailed daily home program. This combination of Traditional and Integrative Therapies was critical in helping Levi recover his full functionality and continue to exceed goals and expectations in the years to come.

Three powerful impacts this had on our family life were: (1) Levi developed a capacity to meaningfully engage and play with his younger brother; (2) He learned to expressively communicate a "yes" which opened up the world of choice making; (3) Levi's relationships with family and caregivers flourished because of his increased capacities to engage with the world around him.

When Western Pharmaceuticals meet Eastern Philosophy

In his poem The Guest House, 13th-century Persian poet Rumi writes:

This being human is a guest house. Every morning a new arrival. A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor. Welcome and entertain them all!



...Be grateful for whatever comes. because each has been sent as a guide from beyond.

As parents we have taken an attitude of hospitality when it comes to navigating questions about symptom management for Levi. We have learned there is no perfect tool, strategy, or philosophy that can single-handedly offer him relief or recovery. Rather a combination is most effective. Given Levi's medical complexities, the combination of "what-works-when" changes frequently. It feels as if every day there is a new arrival of symptoms, more so when he is sick, and our nimbleness within the art and science of his care plan increases our aptitude for hospitality.

In this story we learned how to better utilize the benefits of Western pharmaceuticals when Eastern philosophy is welcomed into the larger picture of care.

Given Levi's severe brain damage, one of his greatest challenges in life was managing his oral secretions. With an inability to swallow the 2-4 pints of spit his salivary glands generated daily, spit was a constant threat to his health, particularly his lungs. Layer in changes in body temperature, seasons, allergies, and a common cold; spit was Levi's arch enemy. This challenge caused him enormous physical and emotional stress. As his parent, managing his oral secretions was one of my toughest jobs.

First, we befriended liquid Robinaul. Then came Zantac in the event his oral secretions were being generated by reflux. Then came bitter tasting Atropine drops. No matter what we tried, or how we timed the medications, Levi's oral secretions were worse at night, particularly in the early evening hours.

It wasn't until we established a relationship with an Integrative Therapy provider educated in Chinese Medicine that we learned about the Yin-Yang influences upon the body when day becomes night. This shift requires our body's internal temperature to increase in proportion to the decreasing warmth of sunlight. When this shift isn't balanced, "wetness" in the body increases, particularly in the form of oral secretions. This imbalance can be particularly noticeable in children and seniors. Temperature regulation, particularly keeping warm, was also one of Levi's challenges.

Our provider taught us simple strategies to help boost Levi's body temperature leading up to and during sunset. These strategies included coming in from outside before sunset began, putting heated rice bags near his kidneys, bundling him or adding additional warm clothing, waiting till after sunset to change into pjs. We combined these with stress reducing strategies we learned from Levi's palliative care Music Therapist.

Implementing these strategies improved Levi's battle with oral secretions during his most challenging part of the day. This in turn reduced his physical and emotional stress, reduced the quantity and frequency of medications needed, and opened the door more meaningful family interactions during dinner and bedtimes. We spent less time helping Levi wrestle with a clear airway and more time gathered around the dinner table. This resulted in significant improvements in quality of life for our whole family.

Expanding our toolbox to include Integrative Therapies has radically transformed our ability to care for Levi and improve quality of life for the whole family. We are deeply grateful for all of our providers who collectively help us live our values while navigating Levi's medical complexities.



a Person-Centered Care

In our home, we highly respect our dependence upon Western Medicine while also giving equal value to the wisdom, strategies, and tools of both worlds. We hope for the day when insurance companies will do the same.

(Optional to include the below list. Thought it might be of interest for readers to see larger scope of the modalities/approaches we utilized. I know not all of these are formally considered "Integrative Therapies," however none of them are covered by insurance, therefore they are outside of the box of "Western Medicine")

Overview of Integrative Therapies utilized for Levi Shu (not covered by insurance) Neurological Development, Physical/Movement Development, Communication * Craniosacral * Reflex integration (multiple approaches) * MNRI (Masgutova Neurosensorimotor Reflex Integration) * Massage * Music Therapy * PT combined with Water Therapy * HBOT (Hyperbaric Oxygen Therapy) * Chiropractic * Tactile cueing * Lily Nielson's Little Room

Symptom Management

* Naturopathic Doctor * Chinese Medicine * Homeopathy * Native American herbal medicine * Local herbal tinctures * Herbalist * Essential oils * Bach flower remedies * Homeopathy * Acupuncture * Supplements (multiple) * Chiropractic * Music Therapy * Massage Therapy * Healing Touch

Spiritual Health

* Prayer * Reiki * Healing Touch * Qigong * Music Therapy

Nutrition

* Supplements (wide variety) * Homemade formula * Juiced fruits and vegetables * Organic farmer CSA partnership * Mother-to-mother breast milk donation

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Reiki in a Pediatric Palliative/Hospice Setting

Benedicte Thymann Nielsen Marcus's Mother <u>benedicte@thymann.dk</u> www.benedictenielsen.com

Leukemia Hit

My son Marcus was 8 years old when the oncologists at Texas Children's Hospital (TCH) in Houston diagnosed him with aggressive leukemia (ALL). Prior to his diagnosis, he was a healthy and active boy. Tragically, Marcus did not respond to the induction and the doctors decided to administer a series of intensified chemotherapy infusions with the highly effective drug Nelarabine. Marcus went into remission but during the treatment, he suffered devastating neurological side effects and ultimately became comatose. MRIs revealed he had global and irreversible brain damages and that he would never recover.

As Marcus remained unconscious and the neurologists noticed no progress for weeks, my husband and I felt helpless. We were not ready to give up on Marcus and reached out for help. A palliative oncologist suggested we try Reiki for Marcus in an effort to ease him back into life. My husband and I had never heard of Reiki but felt this was our only chance to help Marcus when traditional Western medicine failed.

The Benefits of Reiki

Reiki, which originates from Japan, is a form of alternative medicine called energy healing. The current upgraded name for Reiki is Holy Fire III Reiki. Reiki practitioners use a technique called palm healing or hands-on healing through which a "universal energy" is transferred through the palms of the practitioner to the patient in order to encourage emotional or physical healing. If one's "life force energy" is low, then we are more likely to get sick or feel stress, and if it is high, we are more capable of being happy and healthy.

Usually the recipient lies down on the back with eyes closed while the healer works.



KAR NHPCO Leading Person-Centered Care A Reiki treatment feels like a wonderful glowing radiance that flows through and around you. Reiki treats the whole person including body, emotions, mind, and spirit creating many beneficial effects that include relaxation and feelings of peace, security, and wellbeing.

Reiki is based on the understanding that the human body has seven major energy fields called chakras. Each chakra is associated with a specific color. On the physical level, each chakra relates to certain parts of the body. The goal for a Reiki session is to refill depleted chakras with energy in an effort to balance all the major chakras and thereby allow the free flow of "life force energy." At the conclusion of the session, the recipient's body and mind are in complete harmony and the person feels tranquil and blissful.



Getting Started

With little effort my husband and I located a Houston based Reiki Master who immediately accepted Marcus as her client. She came to TCH twice a week each time working for about 45 minutes. After two weeks of treatment, Marcus started to show tiny signs that he was waking up. Even though they were not purposeful actions, he opened his eyes very little, later he moved his arms, and ultimately his legs.

Over the course of several months, Marcus' neurological status improved albeit at that point he did not regain a normal state of consciousness. Due to his massive brain damages, he suffered from many complications such as dystonia and seizures. Additionally, he still needed care and long-term therapy, which was why he was transferred to HealthBridge, a specialized rehabilitation hospital for children in Houston. There Marcus continued to receive Reiki and little



by little continued to make steady progress. He was more awake and at times responded with purposeful movements. Being still ventilated and G tube dependent but more stable, he was eventually discharged to our home with 24/7 nursing assistance.

Being at home made a big difference in Marcus' recovery. The environment was familiar, undisturbed, and loving. In order to control his dystonia and seizure activity he was already heavily medicated, but we found that the Reiki helped reduce many of his painful symptoms. In fact, his home nurses assessed that sometimes Marcus would be so relaxed after his Reiki treatments that he would do with less pain medicine.

Furthermore, when Marcus received his healing treatments, his home nurses noted that his heart rate dropped to a very healthy level and his sats (oxygen saturation level) improved, as he got increasingly more relaxed. He looked peaceful and without tension allowing him to get the deep rest, he needed so badly to recover.

We also hired a massage therapist who came once weekly for an hour session. The massage therapy complemented the healing sessions as both therapies reduced his muscle spasms and excessive tone while causing no adverse side effects.

The Relapses

Without effective leukemia treatment, the oncologists anticipated Marcus would relapse quickly and for sure within a few months. To everyone's surprise, he remained in remission for almost one year. That in itself was a miracle adding to that fact that Marcus overall showed promising rehabilitation results. Whether this was a coincidence or was partly related to his healing treatments no one can say for sure. Reiki cannot stop biological processes, but I believe Reiki can affect the human body in a positive manner and support the body's healing efforts.

Unfortunately, as mentioned above after one year of remission, Marcus relapsed and this time he became a patient at MD Anderson Cancer Center in Houston. The highly skilled doctors managed to bring him into remission again. Additionally, they felt he was ready to start outpatient rehabilitation at TIRR Memorial Hermann in preparation for a lifesaving bone marrow transplant.

In the meantime, I started Reiki training with Marcus' Reiki Master. She had encouraged me to complete Reiki training so I could work on Marcus anytime and more often than she was able to. At first, I was hesitant to learn something so holistic and mysterious. However, the gentle and yet powerful effects of Marcus' Reiki sessions fascinated me. After I completed the course, my teacher observed how I worked on Marcus. She came with suggestions on how to improve my session. After my trial treatment, she told me I was ready to take over Marcus' Reiki care and that gave me tremendous self-confidence. From that moment, I completely took over healing Marcus.

I enjoyed healing him at nighttime after the home nurses completed his bedtime routines. The house was quiet; I put on calming music and turned on a diffuser with therapeutic aromatherapy to enhance the atmosphere. Marcus was unable to speak or communicate how he felt which caused frustration and agitation on his part. When I healed him, I felt a strong connection to him. His body talked to me in nonverbal ways. I sensed how strong the energy was in his chakras. When one chakra was low, I replenished it with energy. Every time I healed him, I felt I gave him a wonderful and special gift and I enjoyed it. I only had to invest my time in him.



Marcus relapsed again before getting the bone marrow transplant but made it into remission one more time. He paid a high price for achieving remission. This time he became weaker and less alert, sleeping most of the time. Because of Marcus' declining health, we enrolled him in Memorial Hermann's Pediatric Outpatient Hospice Program.

Sadly, the recent chemotherapy damaged his already compromised brain so badly that his seizure activity became increasingly violent. It became obvious to everyone that even with the best seizure medicines and other available drugs on the market Marcus suffered too much. Additionally, his leukemia had developed resistance and relapsed for the third time leaving the oncologists unable to offer any lifesaving treatments.

We decided to keep Marcus at home assisted by his home nurses and outpatient hospice team. We believed Marcus felt safest and most restful at home and we could continue to be around him. I healed Marcus more often and I massaged his sore muscles. The physical touch has a stimulating effect on the body. Simply holding Marcus' hand was soothing for him. I kept up all his wellness routines until the very end. Knowing that I did all these wonderful things for him made his last months less painful for me. I gave Marcus his last healing a few hours before he died. He was in a beautiful and peaceful place surrounded by love.

Lessons Learned

When Marcus got leukemia, I told him I would write a book about his amazing cancer journey. After he died, I wrote a book called "Marcus' Story: Finding Hope and Strength when the Worst happens." The book is yet to be published but you can read more about it on my website <u>www.benedictenielsen.com</u>. In my book, I discuss the importance of Reiki and other coping strategies that proved helpful for me during the two years Marcus was sick.

Anyone can enjoy and benefit from Reiki and anyone can learn the techniques used. Reiki is not religious and people of all religious persuasions as well as those with no religious convictions practice it. For more details about Reiki and Marcus' healer, please visit <u>http://www.houston-reiki.com</u>. For general information, please refer to The International Center for Reiki Training at <u>www.reiki.org</u>

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Integrating Gentle Movement Exercises in Pediatric Palliative Care

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Abstract

Objective: Provide suggestions for integrating gentle movement exercises including Tai Chi, Yoga, and Qi Gong into the care of children with complex conditions and their caregivers in the context of pediatric palliative care.

Methods: We conducted an electronic literature search on PubMed for literature published within the last 15 years containing the terms *Pediatrics, Adolescent,* or *Child* combined *with Yoga, Qigong, Tai Chi, Therapy,* or *Breathing Exercises.* Inclusion criteria were participants <27 years with medical diagnoses or inpatient admissions. Exclusion criteria were mental health diagnoses, single participant studies, and studies not reporting intervention design. We additionally include a case and our experiences.

Results: 16 studies met criteria; involving the following diagnoses: cerebral palsy, chronic headaches, recurrent abdominal pain, cancer, asthma, DMD (Duchenne Muscular Dystrophy), and burns. Studies involved inpatient and outpatient interventions, and both individual and group settings. In the in-patient setting, frequent group sessions, providing individual sessions for children on isolation precautions, and flexibility of timing are important strategies for success. With outpatient interventions, participants in group sessions enjoyed the social aspect, but often cited timing or location as constraints limiting adherence. Including video sessions could be helpful. To encourage compliance, we suggest using terminology such as "breathing exercises" and "gentle exercises" to increase parental openness to interventions, as well as using gentler movements during sessions tailored to patient ability and perceived need.



Conclusions: Many insights can be gained from the current literature to aid institutions wishing to integrate gentle movement therapies into their palliative care model. These include: the mutual benefit to patients and family caregivers; the symptom support provided through gentle movement offerings; the subjective experience of well-being; and the ready feasibility of implementing gentle movement as part of care.

Pediatric palliative care teams are frequently managing the distress, anxiety, and pain of patients and their families. We have seen that incorporating gentle movement and breathing therapies, such as Tai Chi, Yoga, and Qi Gong, into the care of these families while inpatient, including in intensive care, improves their self-reported wellness.¹ By introducing mindfulness activities and gentle movements during inpatient admissions and outpatient clinic visits, several of the parents have voiced they feel calmer and more focused after the short sessions. This is consistent with other pediatric gentle movement studies showing improved mood,² quality of life,^{3,4} physical functioning,⁵⁻⁷ and decreased anxiety post intervention.^{3,7-10} Studies measuring disease-specific outcomes reveal promising results of gentle movement and breathing exercises in improving attention in children with cerebral palsy,¹¹ symptomatology in children with irritable bowel syndrome,⁵ pain and associated school absences at one year post intervention in children with functional abdominal pain,¹² and pulmonary function tests in children with exercise induced asthma¹³ d in select children with Duchenne Muscular Dystrophy (DMD).¹⁴ These benefits provide impetus to continue integrating gentle movement into the care of children as an adjunct to their medical care. The intent of this article is to provide a review of the literature, insight from our experience, and suggestions for integrating gentle movement therapies such as Tai Chi, Yoga, and Qi Gong into the care of children with complex conditions and their caregivers in the context of pediatric palliative care.

We reviewed the past 15 years of literature specific to gentle movement interventions—including Yoga, Tai Chi, Qi Gong, and breathing exercises—in pediatric populations with medical diagnoses or inpatient admissions, excluding mental health diagnosis, single participant studies, and studies that did not detail design of gentle movement implementation. The diagnoses included in the studies are listed in Table 1.

Gentle movement exercises were implemented while children were inpatient in four of the studies. The in-patient settings studied included exercises solely in individual patient rooms and group exercises. Group sessions allow socialization, providing a sense of community to patients, and can be done on the inpatient floor if a playroom or large empty space is available. Discerning optimal timing and frequency of gentle movement interventions was a challenge in both inpatient and outpatient settings. There were multiple strategies that were associated with improved compliance with outpatient gentle movement practices:

- 1. Videos for daily to three times a week home practice (2,11)
- 2. Including socialization at the end of weekly sessions (9)
- 3. Including breathing exercises and gentle movement, including Yoga, as part of a summer camp for children with medical complexity, in this case burn survivors (8)
- 4. Integrating mindfulness activities, storytelling, Yoga games, and music into therapy sessions to encourage participation of younger children.^{2,6,8,11}
- 5. Use of props and modification of movements and intensity to enhance participation of all children
- 6. Use of terminology such as "breathing exercises to lessen stress"

Regardless of the location, Yoga, Tai Chi, and Qi Gong classes can vary from gentle to more strenuous and challenging. Based on our experiences, we ask parents about current health



issues, past experience with movement therapies, and current perceived needs. The sessions we generally introduce are gentler to accommodate all participants regardless of fitness level. Slower, gentler movements tend to bring out calmer, more settled responses—which often seem self-soothing to the families. Our movement practices are safe and not strenuous as we want to offer a quiet, easy nourishing environment to the families, which help them balance all the decisions they must face in the hospital and be better prepared to address the needs of their children.

The following caregiver case from our experienced pediatric occupational therapist, who is also a registered Yoga teacher and certified Tai Chi instructor, illustrates the impact of utilizing slower, gentler movements guided by caregiver needs in the inpatient setting.

One mother in particular seemed much calmer after our roughly 20-minute session. She was a mother of an infant with a rare genetic condition who had traveled across the country for medical care. When I first entered the room and introduced myself, the mother was talking on her phone and asked me to wait as she wanted to speak to me. She had past experiences in massage and Healing Touch. This mother said she had been sitting around **"way too much and was stiff" and desired to work on breathing techniques and Yoga** movements. We worked on some quiet attention to breathing to help her focus on the present. After a few minutes, I incorporated some gentle seated Yoga asanas (movements) which she was easily able to follow. We worked on both the breath and movements, coordinating breath with movement for about 15 minutes. I ended the session as a nurse walked into the room. The mother asked me to wait until the nurse left, and she told me that she felt much calmer, relaxed, and less stiff. She hoped I could stop by daily—as this time meant so much to her and really seemed beneficial.

The following adolescent case models the impact of gentle movement on a patient's perception of self and care.

An adolescent with a neuromuscular condition shared with the palliative care provider that she engages in gentle stretches each morning with her older sister to start her day. The patient shared that she thinks of "reaching toward her full potential" when she is stretching her arms and that she thinks of "gratefulness for remaining strength" when her sister helps to passively stretch her legs to music. The patient shared that he feels strong in this morning moment, even though the muscles in her legs are atrophied. She voiced feeling a relational closeness to her caregiving sister in these shared exercises. She shared that she believes the morning ritual helps her body but also strengthens her spirit in preparation for the day ahead.

These are just two illustrations of the impact gentle movement exercises, such as Tai Chi, Yoga, and Qi Gong, can have on families we provide care for in pediatric palliative care. Though the current body of literature is limited on implementing these therapies in the care of children with complex medical conditions, there are many insights to be gained from the studies reviewed above (listed in Table 1). We can utilize the methodologies of these studies, including their many creative solutions to challenges in accessibility and participation, to broaden the availability and success of movement therapies offered by pediatric palliative care teams.

Summary: This article provided a review of the literature and insight from the care team's experience, and suggestions for integrating gentle movement therapies such as Tai Chi, Yoga, and Qi Gong into the care of children with complex conditions and their caregivers in the context of pediatric palliative care. It is both feasible and desirable to include gentle movement



exercises, such as Tai Chi, Yoga, and Qi Gong, in context of pediatric palliative care. Benefits to the children and their caregivers include physical, physiological, relational, and even existential benefits warranting consideration of integration of these exercises into care of the children and their families.

Table 1: Methodology for Implementation of Gentle Movement Exercises in Pediatric Populations

Participants	Methods
19 children (6-16yr) with cerebral palsy (CP) & 22 parents²	Randomization: MiYoga vs waitlist Intervention: 8 week "MiYoga" program: Embodied mindfulness practices & mindful yoga movement techniques. This involved 20min daily home practice with MiYoga DVD & poster in addition to 6 weekly, 90min in- person group therapy sessions with Hatha yoga, mindfulness meditations, & informal mindfulness activities & games. Two phone consultations over the last two weeks were provided to encourage further practice at home & personalize techniques
42 children (6-16yr) with CP & caregiver ¹¹	
7 patients (11-18yr) with chronic headache ³	Intervention: 8 weekly, 75min classes of Iyengar style yoga focused on postures & breathing techniques. Protocol allowed for adaptation of postures for therapeutic purpose & individual need.
9 adolescents (10- 21yrs) with IBD ¹⁵	Intervention: 8wk period with three 60min in-person yoga classes at weeks 1, 3, & 8 + three 30min online yoga videos per week from home. Videos were used from an app downloaded to smartphones or laptops & accessible anytime. Participants could choose videos based on difficulty and flexibility vs. relaxation.
25 adolescents (11- 18yr) with IBS ⁷	Randomization: yoga vs. waitlist (waitlist group also completed yoga protocol after waitlist period) Intervention: 1hr instructional session with demonstration & practice. Then four weeks of daily home practice with a video.
51 adolescents (14- 26yrs) with IBS⁵	Randomization: yoga vs waitlist (waitlist group completed yoga protocol after waitlist period) Intervention: 6 weeks of twice per week 90min Iyengar yoga classes. Homework was suggested. Participants >25mi away, were given \$10 per session for gas expenses.
69 children (8- 18yrs) with abdominal pain- related functional GI disorders ¹²	Randomization: Standard Medical Care (SMC) + Yoga Vs SMC alone Intervention: 10 weeks of 90min weekly Hatha yoga style classes involving poses, meditation, breathing techniques, & relaxation exercises. SMC= education, reassurance, dietary advice, and fibers/mebeverine.



17 caregivers & 7 pediatric palliative care inpatients ¹	Intervention: At least 1 mindful movement session (mean time of 12min) at convenient timing tailored to patient/family needs in their hospital room.
6 children (5-19yr) hospitalized with cancer and 4 caregivers ⁶	Intervention: 5 therapeutic yoga sessions over 2 months while inpatient. Sessions involved breathing exercises, yoga postures, and relaxation/stress management. Modifications were made to poses and with physical supports so that all could participate. Yoga games, storytelling, and music were incorporated for younger participants. One- hour classes were offered twice per week on the inpatient floor OR in the child's room if the child was on isolation precautions.
11 children (7-16yr) hospitalized & receiving intensive chemotherapy ¹⁶	Intervention: Planned to offer yoga 3 times per week for 3 weeks, but discovered yoga needed to be offered 4-5 days per week to meet goal of patient participation 3 days per week. Sessions included relaxation & breathing exercises, yoga postures, and a period of relaxation. Sessions were modified in intensity based on participants & parents were encouraged to join their children.
16 children (6-18 yr.) hospitalized with cancer/blood disorders and 33 parents ¹⁰	Intervention: Yoga class, based on Hatha yoga, was held in the inpatient unit playroom with dimmed lights & instrumental music. Class lasted 45min & consisted of meditation, safe & easily executed yoga poses, and resting pose. Modifications were recommended as needed.
8 children (5-17yr) with cancer ⁴	Intervention: Two 60min pediatric yoga sessions per week for 12 weeks. Classes were held in the local community & consisted of warm up, poses, group activity, cool down, and final resting pose. Poses were modified as needed.
18 children (10- 17yr) who had completed cancer treatment in the previous 2-24 months ⁹	Intervention: 6-weekly 45min yoga sessions held at one of the study institutions in a large conference room. Based on hatha yoga, poses were modified based on ability and emphasized awareness of breath, strength, endurance, balance, and peace. Participants were also given a DVD and instructed to practice at home twice per week. Refreshments were provided after each session for 15min of informal socializing. Family or friends were invited to participate.
20 children (6-17yr) with asthma; half were exercise- response-positive ¹³	Intervention: Two 60min Hatha yoga sessions per week for 12 weeks. Sessions included breathing exercises, physical postures, and relaxation.



26 children (6-14yr) with Duchenne Muscular Dystrophy ¹⁴	Intervention: 10-month program of Hatha yoga breathing exercises. Children were individually taught the following breathing exercises at follow up clinic evaluations: time O <i>kapalabhati</i> , at 3 months <i>uddiyana</i> , and at 6 months <i>agnisara</i> . They were instructed to perform the sequence of exercises 3 times per day.
40 children (age 6- 12yr) with burns ⁸	Intervention: Four 60min yoga sessions daily over four consecutive camp days. Session involved breathing exercises, physical positions, meditation, yoga games, coping strategies, and messages of well-being.

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Shonishin/Non-Invasive Acupuncture as a Non-Pharmacologic Approach in Pediatric Pain Management

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The Search for Non-Pharmacologic Pediatric Pain Management

The Opioid Crisis was declared a "public health emergency" in 2017 by the U.S. Department of Health and Human Services, which cited an alarming average of 47,600 opioid-related deaths in 2017 alone (HSS, 2017).

In 2018, the Joint Commission on Accreditation of Healthcare Organization, which accredits 77% of all U.S. hospitals, took action to fight against the opioid crisis within hospitals by creating new standards for "Pain Assessment and Management" and included a requirement that all "accredited hospitals provide non-pharmacologic pain treatment modalities" (JCAHO, 2017).

In the search for new pain treatment options, U.S. hospitals have begun introducing, into both outpatient and inpatient care settings, such modalities as: meditation, biofeedback, breathing techniques, gentle movement such as tai chi or qigong and aromatherapy, as well as massage and acupuncture. For pediatric patients, depending on age and ability, this "non-pharm" list can prove to be even shorter.

For example, while acupuncture research demonstrates clear therapeutic value in pediatric pain management (Tsai et al., 2018; Wu et al., 2004), acupuncture needles can be challenging or inappropriate to administer in certain pediatric populations such as neonates, toddlers, children in intensive care units (ICU), or those requiring palliative care, as well as patients that have low platelet counts, a fear of needles, or hypersensitivity to touch due to acute pain levels, cognitive or behavioral conditions such as ADHD or Autism Spectrum Disorders, or past trauma, medical or otherwise.

Moreover, parents often decline acupuncture treatment for their child under the assumption that the insertion of acupuncture needles creates more pain for their child. However, when parents are offered a non-invasive acupuncture option for their child, many families are willing to consent to treatment. Fortunately, recent studies suggest that non-invasive forms of acupuncture are also highly effective in pediatric pain management (Golianu et al., 2014).

Shonishin: Needle-Free Acupuncture Medicine for Children

Perhaps the most specialized form of non-invasive pediatric acupuncture hails from 17th century Japan and is called Shonishin, which translates as "children's needle" (Birch, 2011). While Shonishin is rooted in the same theories of Traditional Chinese Medicine and classical acupuncture, it differs in a few key ways.



First, Shonishin does not use regular acupuncture needles that are inserted into the body. Instead, it uses a variety of handheld tools that are designed to treat the surface of the skin with very gentle, rhythmic tapping, rubbing, pressing, scratching or scraping techniques.

These tools offer a mix of smooth, round, multi-tipped or ridged edges to provide different kinds of stimulus or "dosing," and often are creatively shaped like tiny brushes, miniature wands, or even little people or animals, as a means of disarming young patients. The most common materials used are stainless steel, pure gold, pure silver, copper, brass or, more recently, plastic.

Despite their pointy look, these tools touch the skin with light contact, at steep angles and rarely perpendicularly, and with the practitioner's fingertips as a close guide at or very near the surface of the skin. Moreover, practitioners use their non-tool hand to gently brush over the skin after each application of a tool to create greater comfort for the child, while enhancing both diagnostic and therapeutic result.



Image 1.A. and 1.B. Modern Metal Shonishin Tools (2019).



Image 2.A., 2.B, and 2.C. Examples of Shonishin Tool Hand Positions (2019).

Second, Shonishin rarely targets specific acupuncture points, which are located at precise anatomical landmarks, but rather focuses techniques in specific stroking directions over general regions of the body. For example, instead of using one or two specific acu-points to treat the lungs, Shonishin strokes would instead move distally over the posterior region of the forearm, or Lung channel, or caudally along the upper thoracic area of the back, over the Lung organ itself and the corresponding paraspinal nerves.



This is because acupuncture points and acupuncture channels develop in alignment with anatomical growth and sensorimotor development, so that young children, especially infants, have less developed acu-points than older children and adults. Young children thus respond better to treatments that enliven a broad area of the body, or an entire channel, along which those specific acu-points will ultimately mature.

Third, Shonishin employs the body's largest sensory organ, the skin, to communicate with babies and children. The pressure, rhythm, vibration, softness, direction, pattern, and speed of Shonishin techniques are all forms of stimulation that deliver unique information into the nervous system, brain, and spirit of a child. The child processes that information and then sends back communication in the form of reaction through the skin itself which will demonstrate changes in temperature, tone, texture, and moisture, oftentimes after only a few strokes.

Shonishin for Pain Reduction

A few common responses heard from parents and bedside nurses alike, after a hospitalized child receives Shonishin, is how "relaxed" and "calm" a child becomes after being treated. This is because, among other therapeutic results, Shonishin triggers the release of oxytocin through the stimulation of the free nerve endings known as C-nerve fibres (Wernicke & Michel, 2014).

Indeed, a 2018 study, conducted at the University of Oxford and Liverpool John Moores University, showed that gentle stroking of a baby's skin reduced the activity in the brain commonly associated with pain. From a group of 32 infants who all required medicallynecessary heel lance blood tests, 16 were lightly stroked with a soft brush, just prior to the lancing, at the exact rate of 3 cm/second, while being monitored with an EEG.

While all 32 of the infants exhibited the same limb reflex withdrawal, the experimental group showed greatly reduced noxious-evoked brain activity on the EEG (Gursul et al., 2018). Furthermore, the experimental group that received the gentle brushing showed a 50% decrease in duration of facial grimacing after the heel lance. The researchers suggest that the brushing reduces pain perception through the stimulation of C-tactile (CT) afferent nerve fibres.

Shonishin affects not only C-nerve fibres of the skin, but also many of the other neuroanatomical structures contained within the epidermis and dermis, such as Merkel cells, Ruffini corpuscles, hair-follicle receptors, Pacinian corpuscles, Golgi tendon organs, and muscle spindles. Shonishin stimulates these structures to create a unique neurophysiological response and therapeutically influence the sympathetic and parasympathetic nervous system, muscle tone, fascial tone, lymphatic function, proprioception, and pain modulation (Wernicke & Michel, 2014).

Safe and Effective Inpatient Delivery of Shonishin Treatment

Shonishin is an easy and effective intervention to deliver in an inpatient setting. It requires no special accommodations, other than a trained practitioner, usually a Licensed Acupuncturist (LAc), plus a small tool, and about 5-10 minutes of treatment time, depending upon the age of the child. For most children, including babies, two or three short Shonishin treatments per week create maximum therapeutic result, with positive outcomes often witnessed in the very first treatment.

In addition to treating pain, and because of its varied effects on the nervous system, Shonishin can be used effectively for many of the other issues commonly faced by patients in pediatric



hospitals such as: opiate-induced constipation, diarrhea and blow-outs, feeding intolerance, poor appetite, bloating, colic, fussiness, restlessness, excessive crying, anxiety, behavioral disorders, hypersensitivity to touch, sleep disorders, hypoxic-ischemic brain damage, hypertonicity, tachycardia, frequent infection, low oxygen saturation levels, and asthma.

For inpatient care, only simple Shonishin tools with flat surfaces should be selected for use and must be disinfected before and after each use with 70% isopropyl alcohol, in the same manner as a stethoscope. However, for immunocompromised patients or patients suffering from infectious disease that can be spread via the skin, a newly developed, single-use, sterile, disposable Shonishin tool made by the Japanese-based Seirin Corporation is recommended.



Image 3. Seirin Shonishin Box (2019).







Image 4. Seirin Shonishin Tool (2019).

Contraindications for Shonishin treatment include: fever over 100F (37.8C), skin rash, open wounds, lesions, and immediately after bath. Indications of Shonishin over-treatment include: increased fussiness, hyperactivity, excessive fatigue or sweaty skin, though a mild increase in skin moisture is a positive indication of treatment. Because of its extremely mild approach, adverse events from Shonishin treatment are rare.

Indeed, "Less is more" is a guiding principle of Shonishin because over-stimulation of a child is an unwanted outcome. Moreover, Shonishin treatments build on one another to create an entourage effect, so no singular physiological result is sought in any given treatment, rather the practitioner looks to create a greater sense of well-being, calmness, and comfort in the child with each session.

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Photographs

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Music Therapy and Yoga: Stretching the Limits of Care

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Music therapy, an evidenced-based field, provides the opportunity to address non-musical goals associated with physical, emotional, cognitive, behavioral, and spiritual needs. Yoga provides the opportunity to use movement and breathing to regulate the body and mind. Both are homeopathic, complementary, and can be beneficial in attaining balance and regulation in a variety of ways. This article explores how music and yoga were combined to provide comfort to pediatric patients with life-limiting and terminal illnesses to address both physical and emotional goals.

As many pediatric-specialists and clinicians can attest, working with children can be challenging. There can be both complication and reward with the added complexity of a child having a terminal or life-limiting illness. Complementary and integrative modalities, such as music therapy, have proven to be a credible and successful tool to connect with children as they navigate such illness and change. The integration of another modality, such as yoga, adds to this ability to connect by opening a new door to address a variety of goals. It was the interest of one yoga instructor in working one-on-one with children in hospice and palliative care that brought the opportunity to incorporate yoga with music therapy. Through all of the "success" stories, we saw that many of our pediatric patients were observed with and reporting increased relaxation, confidence, and emotional regulation and coping. In addition, there were reports of less anxiety, better/easier movement, and decreased pain when repositioning or during physical therapy and occupational therapy sessions. The use of yoga was able to have more success as the music created a safe and relaxing space through live, responsive music, play, and rapport.

Case Study: Erin (name has been changed to protect privacy)

Like music, yoga can be modified and adapted to be beneficial to a wide variety of ages, abilities, and personalities. In the case of Erin*, a teenager on the palliative care program, yoga and music together proved to be very beneficial. Erin was diagnosed with a neurodegenerative disease at a young age that progressed throughout her teenage years to take away her ability to stand, walk, move her arms with control, and do many simple and normal tasks by herself. As a teenager, the losses obviously affected her physically, socially, and emotionally. In music therapy sessions, Erin was captivated by the use of lyric analysis and improvisation to describe her thoughts, fears, feelings, and hopes. She discussed pain, lowered self-esteem due to loss of function, decreased confidence due to weight gain caused by excess sitting, and anxiety related to all of the aforementioned. The trust and rapport developed through music therapy interventions where she felt heard and validated allowed for the introduction of a new concept-music and relaxation-to combat those negative symptoms and thoughts. Erin explored various techniques during music therapy sessions that included music and imagery, guided imagery, progressive muscle relaxation, and meditation. This exploration led to the concept of integrating stretching and releasing. Due to her condition, Erin had difficulty fully relaxing her muscles and often experienced pain from sitting. The yoga instructor,



who is also trained in Thai massage, offered to co-treat with the music therapist to find ways to stretch, release, and breathe through the pain and discomfort. The ability to do something active, such as yoga, that was both low-impact and doable, also allowed Erin to feel that she was "doing something" to combat the weight gain that came with sitting in a wheelchair all day.

Not to say that teenagers aren't open to trying new things, but there often has to be a "buy-in" or a level of trust to get to that point. In Erin's case, I needed to step up to provide support as she tried this new method in order for her to "buy in" to the intervention. I would try each exercise first, proving that it wasn't weird or scary and modeling the benefits of the stretch. As Erin observed, she was encouraged to ask questions and to get to know the instructor to feel more comfortable. Erin's turn came and music was then offered to continue the music therapist's support and camaraderie. The result was a previously hesitant teenage girl immediately relaxing into the yoga poses and making positive comments like "I don't think I've ever felt that muscle," "Ugh! That has been bothering me for months," and "I am so loving this!" A brief guided imagery was offered at the end of each session. Erin was noted with complete relaxation in her arms, hands, legs, and face. Her breathing was able to slow. At the end, she shared "I finally turned off my mind."

Case Study: Sara (name has been changed to protect privacy)

Although the most commonly identified primary goals of yoga are centered on the concept of relaxation, there is a lot to be said about the structure that the routine of yoga can provide for children. Sara*, a three-year-old with spina bifida, had a lot of behavioral concerns due to lengthy time in the hospital without structure or reinforcement. When first participating in music therapy, Sara was usually only able to play and interact through instrument playing and other music therapy interventions for approximately 10 minutes. It was not uncommon for her to scream when hearing the word "no" or to become inconsolable when crying after not getting her way. Many behavioral techniques were used in conjunction with education to her parents on how to reinforce appropriate behaviors. One of the possible complications of Sara's behaviors seemed to be her inability to express herself through language because of some observed delays, as well as her inability to move independently because of her physical condition. At times, Sara would become frustrated with her inability to communicate her needs and preferences. Yoga was introduced as a way to help Sara have a better awareness of her body, provide gentle assistance when moving, and to add a new element of play and movement into music therapy sessions in an effort to increase her attention span. When working with children, it is safe to say that all clinicians should expect the unexpected. This case was no different. Sara's parents had their concerns about her ability to follow directions and cues and whether or not she would actually be able to do it. Surprisingly, she was able to follow the yoga instructor while music was offered with clear and repetitive prompts simultaneously with what the instructor was doing. Not only did Sara follow the movements with good accuracy, she was able to focus for 20 minutes the first time and remained in a positive mood throughout. Remember: expect the unexpected.

As time progressed, there would be days where she would excel and days that were difficult, just as anyone with a child understands. The most interesting outcome of this experience, however, was her ability to learn a new coping mechanism. Sara completed



music therapy and yoga sessions for approximately four months. Yoga poses would be used throughout the music therapy session to reinforce concepts such as body part identification, cause/effect, and breathing techniques. Through these sessions, we noticed her ability to begin generalizing the poses she was practicing outside of the sessions. The best example was her use of child's pose, which had been practiced as a way to "take a break." In this pose, the knees are bent on the floor as the chest and head lays down over them and the arms are stretched out above the head along the floor. During those periods of inconsolability noted earlier, Sara was able to stop and put herself into child's pose as a way to cope with overwhelming feelings *independently*. She learned a new concept through music therapy and yoga: the ability to self-soothe.

Although utilizing modalities such as music therapy and yoga can bring great benefit to pediatric patients, there are also potentials for harm and thus limitations and cautions should be noted. In the cases listed previously, the yoga instructor had hundreds of training hours, a decade of experience in teaching yoga, was certified in child-based yoga and chair yoga, as well as trained in Thai massage techniques. Much like you would not use a musician from the local bar to do clinical music therapy, you would not want to use an unqualified yoga instructor. Furthermore, there must always be respect for physical limitations. Consulting with a child's physical or occupational therapist prior to utilizing yoga is good practice. Always be aware of trauma, especially related to touch. And finally, as clinicians, it is imperative that we recognize that consent and assent are crucial to care. Both the parents *and the children* must provide consent or assent (if under legal age) before participating in the above case studies as well as in work with other children that utilizes music therapy and yoga.

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Music-Thanatology for Pediatric Patients

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Music-Thanatology is a palliative modality, which uses live music on harp and voice to alleviate pain and suffering at the end of life. Music-thanatologists offer an approach through music that emphasizes the common experiences that we all share, things like: breath, pulse, tension, temperature, stillness/activity, pain/peace, effort/ease; the subtle facets of life as a human. They bring this individually tailored music to the bedside when death approaches—when patterns are shifting, and body systems are failing. In fact, the Greek root *Thanatos* is a reference to the god of the gentle death. Music-thanatologists establish a connection between the basic building blocks of music (things like rhythm, harmony, and melody) and the physiological presentation of the patient. Moving in tandem with these essential aspects of our lived experience as human beings has the benefit of avoiding concerns of language, culture, and religion. Using music prescriptively is a simple, clear way to connect with the breath, the pulse, and the emotional/ existential state of the patient, as well as their friends and family.

Authors Malloch and Trevarthen (2018) give technical voice to the notion that humans are musical beings, pointing out that this holds true from infancy, and likely precedes birth. We know that auditory function begins around or after 20 gestational weeks (Hill, 2016), and that the prominent features of the auditory environment in utero include the mother's voice, heartbeat, and footsteps. David Teie (2016) argues that these experiences in the womb form the basis for all human musicality.

In our practice at JourneyCare Hospice, we receive calls throughout the day, and try to see patients within 24 hours of their referral during a regular work week. The interdisciplinary hospice team (doctor, the nurse, the social worker, chaplain or CNA), gives us a report that includes the patient's diagnosis, age, reason for the referral, religious preference and any other psycho-social issues that may be important.

When we arrive at the patient's home, long-term care facility, hospital, or one of our five specialty inpatient hospice units, the extended family and close friends will often be in attendance. The music vigil (as we call our visits) can become an opportunity for loved ones to come together for mutual support, or to say goodbye. When a child is dying, families and friends are often unsure how to be, or what to say. Many people get their notions about what dying is like from watching movies or from TV, and this leaves them ill-prepared for what happens when someone actually dies. The hospice or palliative team provides extensive information about what to expect, and a music vigil can foster the possibility of coming to terms with the impending loss in a shared but potentially wordless way.



Bringing in a harp, even a small one, gives the chance to move unneeded equipment out of the way and get some chairs near the patient, because often the bedside is arranged for the work of providing care, and not for the comfort of those gathered. Then the music-thanatologist greets the patient—regardless of their ability to respond—and does a pre-vigil assessment. We not only check the radial pulse rate, but we also gauge the quality of the pulse. Does it have a clear ebb and flow, or is it thready, irregular, or impalpable? We gauge the temperature of their limbs and their forehead. We note the respiratory rate, depth, and effort. We also make use of the Face, Legs, Activity, Cry, and Consolability scale (FLACC; Voepel-Lewis et al., 2010), and the Respiratory Distress Observation Scale (RDOS; Campbell, Templin, & Walch, 2010).

As the music begins, the music-thanatologist weaves together the building blocks of music in response to what is happening with the patient's physiology. For example, the tempo of the music might connect with the pace of the patient's breathing. The use of dynamics (a.k.a. volume) could mirror what is happening in the waxing and waning of breath effort. The ambitus or range that a melody covers, could correspond to respiratory depth, fluctuating agitation, or even the flow of thought—whether cyclic, chaotic, or tranquil. The manifestations of body processes have musical correlates, and just as the body changes from one moment to the next, so too does the music. The result is a contemplative, peaceful musical offering that is restful and nourishing. Live music that is crafted in the moment is entirely unique to that situation, bringing everyone's awareness to the present, free from expectation.

Sometimes the music vigil is an opportunity for tears to be shed. At other times, the family simply rests, or even falls asleep. The exhaustion of being a caregiver, particularly of a child, is huge and overwhelming. The music vigil can provide a physical and emotional respite.

We'd like to share a case example to illustrate some of these points:

I was called to see Tammy, who had just been brought home after she and her family decided to stop dialysis and TPN. She is in her early teens and has acute T Cell lymphocytic leukemia which relapsed after chemo, radiation, and a bone marrow transplant. She experiences persistent nausea and frequent emesis, as well as nociceptive and neuropathic pain. According to report, she is very itchy, and doesn't like to be touched.

I arrived to find her reclining in a specialized wheelchair, with a knot of concerned adults around her. She was breathing 56 times per minute, with short, sniffing inhalations and frequent moans and grimaces. She was able to give faint, mumbled responses when spoken to, and appeared to be reassured by those present who swiftly and soothingly attended to her. She did not appear to be bothered by touch, and it was no problem for me to check her radial pulse, which turned out to be too faint to palpate. Her upper extremities, though, were hot.

I began music on the harp, pacing along with her breathing, but at an expanded ratio (so one beat for every 4 breaths, rather than 1 for 1). Several of the women present began to rock themselves back and forth, self-soothing as their grief poured out of them. Tammy's mother was rocking the most persistently, tears streaming down her face as she stroked Tammy's fingers over and over, ensuring that her daughter knew she was right there. Of necessity, the music I played was in a steady meter, giving a framework for the rocking and stroking. After about 10 minutes, Tammy's breathing had slowed from 56 down to 48 per minute, still shallow, labored, and with intermittent, but slightly less strident, complaints.



During the second suite of music, I struck a balance within the music between the pace of her breathing and the rhythm of everyone who was rocking. Together, the collective movement of the group slowed with carefully employed rubato in the music until all were in synch with Tammy's slowing respirations. At the end of the second suite, her breaths were at 40 per minute.

The degree to which Tammy's respirations were slowing indicated a significant and steep decline in her condition. The JourneyCare hospice nurse Lisa talked to the family, answering questions, and preparing them for the fact that Tammy might stop breathing for a period of time, but that she might start up again. The music continued, growing more spacious as emotions calmed. As we watched, Tammy stumbled into one of the breathing pauses that the nurse had warned about, and Tammy's father reminded everyone that this was expected. I took the opportunity to point out that Tammy had been tapering down very steadily, and the father latched on to this description as he prepared another young son for what was going to happen; "breaths getting slower and shallower." Still, Tammy was moaning and grimacing. Each twinge was heart-wrenching for the family. The nurse administered more medication and repositioned Tammy to ease her respirations. In the new position, Tammy's distress appeared to drain away, as evidenced by her vocalizations ceasing, her body stilling, and her brow smoothing. I could see her breaths becoming irrevocably shallow. Her eyes were partially open and rolled back, unseeing. Someone commented that she was cooler, which made sense, considering how little air she was moving compared to what she had been doing 45 minutes ago. The nurse had warned them that Tammy could not keep up that initial breath pace, and that exhaustion would eventually take over, which is what we were seeing now. More people arrived at the home, and there was a sudden flurry of activity that drew everyone away. Somehow in this big, beautiful, bustling family, in that moment, it was just me on one side of Tammy, holding her hand, and her mother on the other side, doing the same. I sang; just simple tones calling out and repeating as Tammy's breathing tapered down, becoming slower and slower.

As the crowd finished with greetings, new tears, and rearrangements, they saw that Tammy was changing, and heard the implication of my simple singing. I moved out of the way as they surged forward to buffet her with words of love, and tears of loss. I took my harp and went into a corner to make room for family to be near her. In the corner was a little two-year-old boy by himself. I had noticed he had been watching me at the harp for some time, so I sat down with him as the nurse talked to the family, shepherding them through the last moments of Tammy's life. When the nurse finally made the **announcement that Tammy had died, the family's grief boiled over**, and several of them fled the room in tears, while others stayed where they were and sobbed. The little guy and I talked about the harp, naming the colors of the strings. I asked if he wanted to play it, and he said he did. While the storm of grief raged, the second-littlest of the family tinkled quietly on the harp in the background. After a few minutes, I explained to my little buddy that I was going to play some more, and he said, "OK."

This last song was lighter, with more melodic movement, and also quieter; firmly in the background. We were no longer tied to the work of each breath or the cadence of rocking or stroking in the anticipatory grief. What the music did now was to carve out a protected space for all: those that weren't done with this initial flood of sorrow, and those who had moved on to practical matters. After a few minutes, all tears had subsided, and the music did too. I went to pack up my harp in the kitchen. There I



encountered Tammy's mother, coming out of a back room, spent from crying. She thanked me for coming, with great seriousness and flat affect, calling me sir. Other sober thanks found me on my way to the door, but mostly I was able to slip out without fanfare, as the hospice nurse continued to guide them through next steps.

Music-thanatologists are rare. According to the Music-Thanatology Association International (www.mtai.org), there are about 100 certified music-thanatologists in the world. So, what can you do if this sort of support interests you, and the hospital or hospice where you are does not employ one? Here are some thoughts:

- You can, of course, advocate for your hospital or hospice to look into employing a musicthanatologist.
- You can see if your hospice or hospital offers music therapy.
- Sing. Hum quietly, letting their breath be your guide.
- You can play recorded music but alternate it with periods of silence. Don't leave a recording on repeat, as the poor child receiving the music cannot turn it off, and we all need breaks.
- If your loved one is in an institution, you can advocate to have a quiet, family-friendly space at the end of a hallway, rather than by the nurse's station.
- As a caregiver, you should ask the family repeatedly if they know what to expect as their loved one declines. Go a step further and ask them to tell you what they understand or expect.
- As a family member, you can ask often, "What should we expect? Is there anything I should be asking that I haven't already asked?"
- Remember that death is a part of life. Demystify it. Invite in other children to the **bedside.** You don't have to do this yourself: Call on child-life specialists, social workers, nurses, doctors to help support you through this process. It takes a village.
- Even if you are not religious, invite in the chaplain from your hospice or hospital. Let them create a ritual for your family involving music while your child is still alive. Don't wait for the funeral.
- Laugh, tell stories, cry, cuddle. Invite in your village. If you don't have a village, tell the hospice or hospital and let them create one for you.

Because we are all musical beings, music simply represents what we all need: comfort, space, support, and love.

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Art Therapy at Camp Kangaroo

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Before reading this article (and only if it is comfortable for you to do) try to think back to the first time you experienced the death of a loved one. Then, answer the following questions:

- 1. Who is your "special someone?"
- 2. How old were you when they died?
- 3. What was your immediate reaction/response?
- 4. How did this experience change you?
- 5. What did you do to move forward?

Anthropologist and scholar John L. Caughey emphasized the importance of the individual in cultural studies, stating that "each individual forms a part of multiple cultural traditions as they create and negotiate identity on an everyday level" (Caughey as cited by Talwar, 2010). "Cultural traditions," such as those surrounding mourning and loss, "arise from intersections of race, class, gender, education, nationality, sexuality, and so forth" (Talwar, 2010). In other words, a person's family, cultural background, gender, or socioeconomic income are just a few of the factors that can change the way that we experience loss, physically and emotionally. For anyone, the introduction of death as an inevitable outcome of life introduces a sense of vulnerability that most likely did not exist prior to experiencing loss. In children and adolescents, this vulnerability is compounded with the emotional turbulence necessary to human development. Depending on the age group, this can result in signs of distress from temper tantrums to difficulty concentrating and may even lead to suicidal thoughts.

In order to address this issue, several hospice agencies have begun to organize "bereavement camps" which are designed to give children and adolescents the opportunity to process their grief through sharing and participating in therapeutic group activities. Since 2012, Seasons Hospice and Palliative Care has been facilitating an annual bereavement camp called *Camp Kangaroo*. Based largely on William Worden's Tasks of Mourning and previously existing bereavement camp models, Seasons' physician, Dr. Russell Hilliard, designed Camp Kangaroo utilizing psychotherapy and creative arts therapy approaches to guide children through the grief process. Beginning with the Worden's first task "To Accept the Reality of Loss" and ending with task four, "To Find an Enduring Connection with the Deceased while Embarking on a New Life," the therapy groups at Camp Kangaroo are facilitated in a specific order, as follows:

Session 1: Finding Our Commonalities Session 2: Death as Change Session 3: Grief Emotions Session 4: Dealing with Sorrow Session 5: Dealing with Anger Session 6: Ask the Doctor Session 7: Memories & Remembrance Session 8: Moving Forward Through Grief



Following this model, Seasons' employees and volunteers come together beginning months in advance to plan a unique camp experience each year. Seasons' Supportive Care staff made up of counselors, social workers, chaplains, music therapists and art therapists, create the session plans and facilitate the therapy groups during camp. Campers are broken up into age groups with counselors and volunteers assigned to support each group. Once the counselors are assigned to a group, they create a camp syllabus based on the session concepts listed above.

Art therapy interventions are ideal for addressing the concepts presented during Camp Kangaroo sessions. To quote art therapist, Melissa Raman Molitor, "Art and ritual allow for the maintaining of the connection or bond with the deceased. The nature of ritual and art making also provide a connection to the community, the culture and the whole of humanity in the shared experience of grief that is lacking in our culture. Children and adolescents express themselves more easily through a form other than verbal. They have more immediate access to images and symbols than words and can express themselves through the art process without having to intellectualize their feelings" (Raman, 1999).

Art can be physically engaging and active, allowing the artist to focus on storytelling without distraction or influence. After an artist feels a work of art is done, it is then possible to step back and interpret the story and allow the artwork to influence the grief process.

During Seasons' 2018 Camp Kangaroo, "tween" group counselors facilitated an art therapy intervention using popular music, movement, and drawing. After a short discussion Figure 1: *Tween campers "Dealing with Sorrow" through Art and Music*, Photo by Teresa Sit. about what it means to feel sad, campers were asked to anonymously write down their favorite songs to listen to when they are feeling sad on a piece of paper and place it in a bowl. Group counselors used these songs to create a playlist. Campers were told that the song choices should remain a secret and discussed withholding personal opinions about songs. Then, having covered two large tables in Kraft paper and placing a variety of drawing materials in the center of the tables--pastels, tempera paint sticks, markers, and crayons--the songs were played on shuffle. Campers and counselors responded to the songs they heard by making marks on the paper. As each song ended, participants would rotate around the table. By the end of the playlist, the entire table was covered in colorful imagery (see Fig.1).





Figure 1: Tween campers "Dealing with Sorrow" through Art and Music, Photo by Teresa Sit.

Throughout this process, campers and counselors had moments of quiet and moments filled with singing and laughter. Arms stretched and moved across the table, each drawing becoming intertwined with the next, eventually creating one, cohesive artwork. The drawing was moved to the wall, and campers were able to witness it from a distance. Counselors led a discussion to wrap up the session and share feelings about the work, with each participant reflecting on how the music influenced their choice of color, the shapes they drew, and the speed or rhythm at which they were creating. They spoke about how, at first, there was a hesitancy to have a **drawing touch someone else's**, but it became unavoidable as the paper was filled, and eventually, it contributed to the shared sense of collaboration and community. In this sense, campers were taught to recognize coping mechanisms they already relied on, such as listening to favorite songs in times of sorrow. Additionally, campers were able to see new coping mechanisms of socialization and expressive art making.

Art making in all of its forms--paint, sculpture, photography, dance, theatre, poetry, and beyond--is often perceived by society as a luxury. Author and lecturer, Ellen Dissanayake, argues that art is a necessity to living. From her 1992 article *Art for Life's Sake, "* ...in order to include human history, human cultures, and human psychology, art must be viewed as an inherent universal (or biological) trait of the human species, as normal and natural as language, sex, sociability, aggression, or any of the other characteristics of human culture" (p.169).



As educational art programs are defunded and removed from school systems across the United States, it has become more important to supplement creative arts interactions through extracurricular programming such as Camp Kangaroo and other grief camps surfacing around the U.S. Grief camps allow the unique opportunity for healing through the common bond fostered by participants and through the exploration of grief with expressive arts (Hamblen, p.259). Art making supports the process of grief and loss through the process of exploration, reexamination, and communication. In a candid and personal case study on the death of her own mother, art therapist Crystal Drake found "Making art…is giving me a method to respond to past experiences…I feel I am reclaiming my voice and am able to find the strength to continue forward" (2018).

Thinking back to the questions at the start of this article, once an individual is faced with the loss of a "special someone," grief becomes a part of life. To engage in human interaction is to risk grief in exchange for meeting the basic human need for connection. Art allows the individual to make abstract thoughts and concepts tangible, visible. The process of art making can clear the mind of distractions, allowing a story to take shape, giving form to memory. It allows us to give shape to our own individual culture and to share our culture with those around us--to say to someone, "this is how I feel loss, sadness, anger" and to seek camaraderie. Art making provides us with a useful coping tool, a way to bridge connections with others, and a way to integrate past experiences into present-day living. In this way, creative arts interventions used during bereavement camps provides children and adolescent participants with a toolbox for grieving, honoring emotions, and moving forward.

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CLINICAL HYPNOSIS AND HYPNOTIC LANGUAGE IN PEDIATRIC PALLIATIVE CARE

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Introduction

Even though hypnosis has been recognized for many decades as having clinical value and numerous studies have attested to its efficacy, it is not generally considered "mainstream" in the treatment of serious symptoms. This article is an attempt to move this treatment modality along the path of more general acceptance of its potential for great benefit with essentially no side effects or risk. Unfortunately, the mythology associated with hypnosis in movies, books, and cartoons often portrays it as a mystical form of mind control, usually done by a deranged villain with evil intent. Also, not helpful are the stage hypnotists who use hypnosis to make people look foolish, rather than for their benefit. Persons with formal credentials in medicine or counseling, who have been trained under the auspices of medically-accredited organizations such as the American Society of Clinical Hypnosis (ASCH) or the National Pediatric Hypnosis Training Institute (NPHTI) are not to refer to themselves as "hypnotists" because that term is considered a "lay" designation. I have now had over 120 hours of training under these organizations and am now considered an "Approved Consultant" by ASCH. But frankly, before my exposure to and training in clinical hypnosis, I thought it was akin to quackery.

So, what is hypnosis?

Unfortunately, the term does not lend itself to simple explanation. Suffice it to say that hypnotic trance is at the same time a state of extreme relaxation and intense mental focus. The therapist guides the patient into a relaxed state and then helps the patient to use his or her imagination to develop his or her own metaphors and images that are useful in dealing with a specific problem or set of problems. All hypnosis is, in fact, self-hypnosis. The therapeutic goal is to teach the patient how to quickly use those images to speak to the normally unconscious part of the mind in order to manage or control certain symptoms whenever needed, whether at home or in school or participating in some activity. Hypnotic trance is a naturally-occurring phenomenon that we have all experienced but usually not intentionally. Children at play, becoming someone else in imaginary scenarios, are frequently in a self-induced hypnotic trance. We have all experienced driving somewhere and not remembering the trip. The unconscious part of our mind is driving while we are consciously elsewhere. That is a type of hypnotic trance. Physiologic changes do occur with trance such as slowing of breathing and heart rate. In addition, speech is usually slowed and movements that we call ideomotor are slow and often miniscule.



How is it used and what is the evidence for efficacy?

While in a state of hypnotic trance, patients are taught how to control a symptom. For instance, a teenager may present with pain secondary to cancer. First, we spend some time developing rapport (a key necessity) and discussing hypnosis, laying aside fears or misconceptions and emphasizing that the patient will always be in control and can stop at any time. In addition, the close connection between mind and body and how pain works is explained giving examples of how the unconscious part of the brain can stop or diminish the pain signals (gate theory). Then, if the patient wishes to proceed, a state of hypnotic trance is induced, frequently with focusing on breathing (often belly breathing), progressive relaxation, and favorite place or activity imagery of their choice. They can then use just this alone as a way of calming themselves or sleep induction. Then, as an example, the patient may be guided to imagine their pain control center and to look for some sort of control for the pain and then, when they find it, to start to use it to dial down the pain currently being experienced. Most patients are able to reduce their pain somewhat at the first visit and then with practice and perhaps additional sessions for reinforcement the patient becomes more and more skilled at it. The development of this ability is life changing because it not only relieves pain, but it is empowering, giving that teenager some control over the illness and at the same time avoiding the embarrassment of needing to be excused from class to get a pain pill. In addition, the reduction of the amount of pain medication needed is welcomed by most.

Although the example above was pain due to cancer, there are multiple causes of pain and pain syndromes both acute and chronic, that are amenable to hypnotic intervention including migraines and other forms of headaches. There is good evidence in the literature with both descriptive and random controlled trials documenting hypnotic efficacy in controlling anxiety, insomnia, many forms of nausea and vomiting, tics (including Tourette Syndrome¹), and various habits including habit cough. If one thinks of palliative care in the truest sense as a specialty that deals with both life-threatening and life-changing conditions, then Tourette Syndrome or a habit cough so pervasive that the child can't go to school are well within the purview of palliative care.

Hauser et al.² concluded from reviewing meta-analyses of randomized controlled trials involving at least 400 patients that strong evidence exists for the reduction of pain and emotional distress, decreased symptom duration, and reduced drug use during medical interventions. The evidence also extended to the reduction of symptoms due to irritable bowel. Additional published reports^{3,4,5} of meta analyses and controlled trials conclude that hypnosis was helpful in reducing pain in the majority of patients, allowed reduction in pain medication, and sometimes eliminated various symptoms altogether.

Personal Experience

I have now taught self-hypnosis to over 150 patients, approximately two-thirds of which were children, ranging in age from 5 to late teens. The predominant symptom prompting referral was pain, both acute and chronic. Anxiety and insomnia are also common and often part of the pain syndrome. Nausea, vomiting, habits, and tics made up most of the rest. I am not a counselor, so I seldom see patients with complex psychological issues underlying their pain unless it is in conjunction with a counselor. Self-hypnosis was curative in helping a teenager through a severe conversion disorder, but child neurology was heavily involved. Almost all patients are referred by a specialist who is managing the primary problem, so all patients have been thoroughly evaluated medically. I have been at the bedside of a dying young adult whom I had been seeing for pain, and even though she seemed to be in a coma she could hear through the opioid fog and





noticeably relaxed and smiled and then let go as she imagined what heaven would be like. There was a teenage boy who had been in a severe car accident and could no longer talk or move much. His left arm was flexed on his chest with wrist flexion also. But his eyes told a story of comprehension and I taught him to focus all of his thoughts on his left arm which hadn't moved for two weeks and to allow those muscles to gradually relax. Not a dry eye in the room from family, palliative care nurse, and me as we watched that arm slowly fall to the bed and relax. The implications of this and how connected we are and how powerful our mind is in regulating bodily functions cannot be overstated. At the same time, I don't wish to imply that these techniques are successful in every situation and with every patient. They are not. However, the risk-to-benefit ratio is negligible and the success rate extremely high, over 75% in the literature already cited.

Hypnotic Language

While learning how to intentionally induce a hypnotic trance and teach patients how to use these techniques themselves, one learns to speak hypnotically and use hypnotic language. This is not something mystical or magical. Successful therapy with hypnosis is totally dependent on the rapport achieved with the patient. Rapport is highly dependent on careful, empathic, and attentive listening. When we listen empathically people know we care about them and that what they say is important to us. That engenders trust and moreover allows the therapy to be tailored to who that person is. The manner of speaking used by the therapist is frequently slowed, cadenced, and even timed to the patient's breathing, all of which has a calming effect. But more importantly, the words used are carefully chosen and begin to become part of our everyday language. The language is permissive rather than directive, as "you may begin to notice" rather than "you will notice." We learn to use words that tend to uplift, encourage, empower, and maintain or restore dignity and give hope. A discouraged patient may say, "This isn't working." A good reply may be simply, "Yet." The values mentioned are as important to a five-year-old as they are to a 75-year-old. Our words should avoid labeling the person as the disease.⁶ Johnny is not an asthmatic. He is a nine-year-old boy who has asthma. The difference may seem subtle, but it is not. If we say asthmatic, it defines him and causes him (and others) to think of himself as his illness. If he is just a kid with asthma, that problem can be compartmentalized and relegated to a nuisance with which he must deal for sure, but it does not define who he is. During the hypnotic session, we frequently comment on what the subject is doing to let them know we are paying attention. So, if little Johnny is squirming in his chair, we can say, "that's right, get yourself comfortable." This encouragement furthers his relaxation and trance. These same techniques apply to ordinary interactions in everyday conversations with patients, coworkers, friends, family, and even strangers. They are all based on empathic listening, being attentive, not being dismissive, responding to things said that have emotional content, and developing compassion even for those with challenging personalities. It is often possible to insert therapeutic suggestions for our patients and family who are stressed. So with a patient or family member with whom a supportive positive relationship has been established, a slowly delivered suggestion, made with good eye contact, may have surprising effect, such as, "you know what, I'll bet that tonight you may be able to sleep better than you have for a long time and awake feeling really refreshed." A casual inquiry the next day may reveal how powerful that simple suggestion was. It is within our capability to make all whom we meet feel just a little better about themselves. In the same way a positive comment may be helpful during therapeutic trance, so we can change the day of the housekeeping employee by being grateful for the good work in making things so shiny and clean in our hospital.



Summary

Clinical hypnosis is an evidence-based, highly-effective tool that can be used to treat common symptoms encountered in the practice of palliative care. It essentially has no risks or side effects and is quite satisfying for the practitioner because of the frequency of an immediate positive result. Formal training may be obtained through ASCH or NPHTI and course schedules are available on their respective websites.

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Pediatric Massage: A Gentle Approach for Pediatric Palliative Care

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No one wants to think of a child being too ill to play with their friends, or to even venture outside. Our hope is that they will get better and the memories of their time in the hospital, or healthcare system, will soon be in the past. This is not always the case with children in palliative care.

It is important to remember that children and their families may suffer not only physically but also emotionally, during all stages of chronic and life-limiting conditions. This pain may come from symptoms of the child's condition, as well as from side effects caused by curative treatments and the stress and anxiety caused by concerns related to the child's diagnosis.

When a child is facing a complex medical diagnosis, the healthcare providers and the child's parents face many decisions and the reality of choosing between the benefits of using often invasive medical treatments or providing comfort to improve the child's quality of life.

Why Pediatric Massage?

Many people think of massage therapy as a luxury and do not recognize the healthcare benefits associated with this noninvasive integrative intervention. For children and families living with and managing serious illness, pediatric massage is an essential and necessary component to provide comfort and quality of life.

Patients in pediatric palliative care are those who have been identified as having an incurable chronic illness, leading to shortened life expectancy. These patients are often subjected to invasive medical treatments and would greatly benefit from being provided with interventions which aim to bring comfort, compassion, and relief to the physical and emotional symptoms they experience.

When using massage therapy for children, the approach and techniques should not be aggressive to reach maximum benefit. Most types of gentle massage (i.e., pediatric massage, light nurturing touch) result in various levels of symptom relief, and those who receive light tough massage report significantly greater reduction in their symptoms.

The Need for Positive Touch

Positive touch is essential to the growth and development of children, but it is so easily overlooked during their hospitalization. Children with chronic conditions and complex medical needs, often develop fear and anxiety surrounding their medical care. They must cope with a variety of stressors, symptoms, and side effects related to their illness and treatment.

Many medical practitioners focus on procedural touch which can become overwhelming and elicit a negative response. In many situations the majority of touch the child has received has



been uninvited poking and prodding, painful clinical touch, or lack of positive touch. Currently, there is much more awareness that this type of treatment can create trauma for children. Providing the gentlest of compassionate touch, and facilitating healthy touch experiences for children and families, can help to restore trust and allow them to become active participants in their healing journey.

A Family-Centered Approach

Each child has unique and specific emotional, physical, and development needs. As much as the focus is on the child's care and comfort, to best care for them, we must focus on the entire family. The child's family is defined as those people in the child's life who provide not only physical and psychological care for the child, but also spiritual and social comfort. This family network may include "family members" regardless of genetic relationships. Family members can be those who are biological, marital, adoptive/custodial, and family of choice including beloved friends and pets.

Pediatric massage can be a very effective therapy providing care and comfort. Not only is pediatric massage therapy applied by specially trained and qualified healthcare providers, families can be taught to safely and effectively use gentle techniques to offer comforting touch to their child and each other.

To many patients and their families, pediatric massage is often seen as a very important part of their healthcare. There are many times when the parents are found sitting bedside for hours on end, often feeling frustrated and helpless within the medical system and with how they might try to ease their child's pain. When the family is empowered to use nurturing touch, they feel much more capable of easing their child's discomforts.

Choices Matter

Children feel more empowered when they have choices. They have so many choices that can take place during a massage session. From the type of lubricant, music selection, or even whether they receive massage at all.

The child always has the right to refuse massage therapy when offered. Giving choices of positioning, lighting, and music allow the child to feel in control and take an active role in his or her healthcare. When giving choices, it is imperative that you give choices that are realistic and not overwhelming. A good example would be choosing between two different types of oils. The child can always choose massage without oil, which is sometimes a better choice considering they often wear clothing during massage time.

The same choice option applies to music. We often choose a specific style of music that we feel **is "massage" appr**opriate. Many clients enjoy our music choices, while for others it is not calming or relaxing. When given the choice, children often choose fun and developmentally-appropriate music, which may or may not be in line with your typical music selection. The music itself is not as important, as is allowing the child to make the choice.

During pediatric massage therapy, one of our main goals is to empower the child to feel he or she is the focus of the session, acknowledging that the child is heard and respected. When



children feel they are an active part of their healthcare, they are much more likely to receive the benefits massage therapy can provide.

Massage Therapy for Pediatric Pain Relief

Pain is one of the most commonly reported symptoms of children in palliative care. A child's pain may increase along with the stress and fear associated with the life-threatening diagnosis. Despite the fact that the modern medical system has the means to relieve a child's pain, many children often suffer with their discomfort.

In addition to the many traditional pharmacological approaches, there are numerous other pain management strategies and approaches, including integrative medicine therapies and nonpharmacological approaches to pain management.

Pediatric massage may not only provide for pain management without the use of invasive interventions, there are a host of broader benefits for the child. Massage therapy can provide a method of relaxation at a time of the family's increased anxiety, stress, and fear. Through the use of this gentle approach, children who are provided with comfort may experience a decrease in emotional distress, physical discomfort, nausea, and gastrointestinal concerns.

Specific Approaches and Considerations

Providing pediatric massage therapy techniques can be very beneficial for children and their families. This gentle modality can be adapted and made appropriate for most pediatric patients even if they are medically fragile. However, as with all care for children, utilizing the safest approach is very important. There are a number of known contraindications and precautions that must be practiced when using massage.

It is important that you do not use oil or any lubricant, if there are known allergies or medical concerns. Additionally, you should never use oil or lotion around any medical equipment, such as lines or tubes. Massage can be effectively applied without the use of massage oil, so often times it is best to skip usage of oil if you are unsure of the concerns.

With approval of the healthcare team, massage may be applied in a very gentle method and achieve a great benefit. First, the parent or therapist should assure that they are aware of any safety concerns, and only give touch therapy if approved by the medical team. With the child awake and alert, the provider should ask the child's permission and take time to explain massage therapy and benefits. Massage therapy will only be provided if the child gives permission. When asking permission, the parent or therapist should warm their hands by rubbing together. If the child grants permission, start with nurturing touch.

When providing nurturing touch, the hands of the provider should always be visible (i.e., never under clothing or hidden from view). Start by placing warmed still hands, gently without any movement, on the child's hand. Gentle, nurturing touch is often safely applied and is very different from medically-involved touch interventions. When you set the intention to provide nurturing touch without medical necessity, it takes on a different form of comfort. Very gently move one hand to another location, such as moving slowly in a walking motion from the hand up the child's arm. You can repeat this action a few times, before moving to the other hand and arm. All the time keep in mind the child's response and respect the child's desire to stop at any time. If the child falls asleep, we would stop the massage therapy intervention as we no longer have permission, and it is likely best for the child to rest. By gently placing your hands, using



nurturing touch, you give the child the opportunity to experience positive touch. During this intervention many children find it quite relaxing to have their favorite music playing or hearing a calming story which allows them to rest.

Nurturing touch provides a high benefit, low risk integrative approach to pediatric palliative care. This gentle physical connection ensures the child knows he or she is never alone. While palliative care strives to provide comfort and support, pediatric massage is an amazing integrative therapy which directly impacts the quality of life in a positive way for both a child and its family.

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Joy and Laughter: Pet Therapy in Pediatric Palliative Care

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Most people reading this article work in pediatric palliative care and understand that a lot of our work is focused on joy and laughter. No matter how sad and heart-rending the situation, our goal is to achieve expert pain (not just the physical) and symptom management to focus on quality of life, joy, and laughter. Our challenge is to get others to focus on the living not the dying.

However, how we get to this point can be challenging; there are many difficult conversations to be had, relationships must be established and built, and goals need to be defined. Sometimes just getting past basic introductions can be the most difficult. One way our program decided to help bridge this was with Sundance.



Sundance is a two-year-old golden retriever who was bred to be a service dog and after two years of training, I was lucky enough to be matched to him. After 14 very long days (and nights) of training to be his handler, we graduated as a team. Sundance is now one of two facility dogs at UCSF Benioff Children's Hospital Oakland and the newest member of our PACT Team—our complex pain and palliative care program. The hospital's first facility dog, Trinity, has been in the Rehabilitation Department for four years.

The benefits of pet or canine assisted therapy are not new concepts. There is considerable literature on the impact animals can make on individuals and groups. It is not our purpose to review that literature, but

we have included a list of articles which may be of interest.

Pet Therapy, aka Animal Assisted Therapy and more specifically as Canine Assisted Therapy, benefits have been documented quantitatively (such as measuring physiological markers in both patients and dogs) and qualitatively (for example sharing experiences). Therapy dogs serve in

various capacities such as facility dogs in very different settings. These settings can include clinics, acute care hospitals, schools, residential care facilities. In these settings, therapy dogs work with different populations such as oncology or dementia patients, veterans, and victims of trauma/crisis. Most of the literature has been on patients in standard settings; little has been written about pet therapy and pediatric palliative care, the impact on staff, or the impact for the handler.

The purpose of this article is to share our experiences with Sundance, what was expected, what we experienced, and what surprised us. A typical day with Sundance usually goes as follows:

1. Getting to office from parking garage (normally a 5-minute





walk) usually takes at least 20-30 minutes due to "informal" consults.

- 2. Informal referrals are requests that come when people see Sundance. They often go like the following:
 - a. Encountering patients, visitors, and staff who ask permission to meet Sundance and then cannot let him go.
 - b. Walking past the lab draw station and being asked to help distract a patient(s) for a blood draw
 - c. Waiting to get on an elevator, the door opens, and suddenly people are getting off and asking to meet Sundance
 - d. Walking past a nurse's station always means at least 15-25 minutes as most members of the healthcare team start appearing from all over the unit asking permission to say hello—which typically means most of the staff sitting on the floor with Sundance on his back getting his belly rubs!

At our facility, formal referrals are placed in the EMR as a palliative care consult where they can add Sundance in the comments section—we use EPIC. Or a verbal consult/request can be made. These consults are most often to visit a child in his or her hospital room, but on occasion there are requests to meet a child in the courtyard, the clinic, or another setting. Sundance has his own patient list and usually 'rounds' in the afternoons, Tuesday through Friday.

There was concern that we would be overrun with consult requests for Sundance and that this would take away from our palliative care program. However, although some referrals have been for anxiety, stress, or for distraction due to a prolonged hospitalization, every patient referred has been an appropriate palliative care referral. Sundance has provided us entry and an ability to establish a relationship where we may not have had an entry before. Sundance has also proven to be expert in helping difficult conversations for patients as well as for parents/primary caregivers and siblings. An added benefit is that since adding Sundance to our PACT Team, our referrals increased over 200% with Sundance carrying a third of our patient load.



I am the mother of four and I often drive carpool; I always want to drive carpool. There is an amazing phenomenon when you are driving carpool. You have a car full of kids/teens/young adults and you are invisible. It is as if you don't exist at all and this means you hear the most amazing/surprising things. A certain way to know what is going on in your child's life! I have experienced this same phenomenon with Sundance; at times it is as if I don't exist even though I am always attached to Sundance. Patients tell him their secrets, their fears, their hopes. Parents do the same. Sundance can provide a sense of normalcy and comfort and can help calm anxiety. He can often be found being walked by a patient(s) as they take their laps around the unit, sitting patiently while a child hangs on during a treatment/procedure, or lying in bed snuggled next to a patient.



All of the scenarios mentioned above can bring a smile to your face; seeing a dog interact with others, a wagging tail, smiles on the faces of the individuals and the dog, what is there not to smile about! But Sundance serves a greater purpose; he opens doors to deeper discussions. Sometimes the discussions are between him and the individual. Sometimes he is the tool that gets a difficult conversation started; providing comfort



during the conversation. I often marvel at his instincts to know which person in the room needs him to be at their side.

There was no doubt that a facility dog would be welcomed and would bring a smile to the face of patients, family members, and staff. What we did not realize was the powerful impact having a dog would make on staff. I remember as a young girl telling my dog all my secrets; she was my best friend. I am still in awe to realize that many of our staff see Sundance in the same way when it comes to sharing their struggles with their work. It is not unusual to receive a phone call and be asked to attend a staff meeting or to come up to a unit to give the staff a break with Sundance. These usually follow a stressful situation, not an uncommon scenario in the regional pediatric trauma center. What has impacted me the most are the chance encounters that happen to be at the perfect time for a particular individual, when an individual falls to his or her knees to hug Sundance to their chest as they whisper or cry into his coat. It is moments like this when I wish I could provide them total privacy. I am always humbled when they thank me for letting them have time with Sundance.

It is not just the clinical staff that have benefitted from having a facility dog. There are support staff, office staff, and others who have asked to have time with Sundance. These staff members may not be directly involved with the care of an individual patient/family, but they are just as affected by the **patient's** situations as those providing direct care. In an informal survey of staff, it was clear that any reservations about having a dog in the hospital and interacting with our patients were far outweighed by the benefits they have witnessed, with most requesting the addition of more dogs. For me, it has been humbling and an honor; Sundance has brought joy and laughter to all of us.



*Sundance was bred and trained by Bergin College of Canine Studies, home of the Assistance Dog Institute, a not-for-profit accredited college; more information can be found at <u>https://www.berginu.edu</u>

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ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. NHPCO Palliative Care Online Resources:

NHPCO has a variety of pediatric hospice and palliative care resources available at <u>www.nhpco.org/pediatrics</u>. Also, more palliative care resources are available at <u>www.nhpco.org/palliativecare</u>, including:

- Community –Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. Join NHPCO Today!

<u>Individual Palliative Care Membership</u> <u>Palliative Care Group Application</u> - Save by registering your entire team

- 2. Pediatric Hospice and Palliative Care Resources:
 - CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. <u>www.caringinfo.org</u>
 - When Your Child is in Pain
 - Talking with Your Child About His or Her Illness
 - Talking to Your Child's Doctor: When Your Child Has a Serious Illness
 - When a Child Dies: A Guide for Family and Friends
 - Helping Children Cope with the Loss of a Loved One
 - NHPCO's Palliative Care Resource Series includes pediatric palliative resources such as:
 - Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy
 - Consideration for Complex Pediatric Palliative Care Discharges
 - 'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning
 - Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care
 - Nonpharmacological Pain Management for Children
 - Sibling Grief



- Pediatric Pain Management Strategies
- Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations
- 3. Trends in Pediatric Palliative Care Research

Every month PedPalASCNET collects new pediatric palliative care research. For past lists visit <u>their blog</u>, <u>browse in their library</u>, or join the <u>Zotero group</u>.

View the New Citation List in their Library

- 4. Pediatric Hospice and Palliative Care Training:
 - Upcoming 2019 Webinars provided by the Pediatric Care Coalition:
 - September 19: Pain Management for Children with Serious Illness in the Context of the Opioid Epidemic Presenter: Stefan Friedrichsdorf
 - October 17: An Expense Worth Expressing: The Role Of Expressive Arts in Pediatric Palliative Care Presenter: Debra Lotstein
 - November 21:
 Compatible with Life: Rethinking Care of Children with Trisomy 18
 Presenter: Nicole Hahnlen & Deanna Deeter



- The 2019 Interdisciplinary Conference will offer peer-to-peer intermediate and advanced educational sessions that will address these specific topic areas:
 - o Community-Based Palliative Care
 - o Interdisciplinary Team Leadership
 - o Medical Care
 - o Pediatrics
 - o Quality



- Regulatory
- o Supportive Care
- Collaborative Interdisciplinary Care for Pediatric Patients: Interactive Case Discussions Sun, November 03, 1:30 PM 4:30 PM Preconference Seminar

Children with chronic, complex, medical conditions inevitably have numerous stakeholders and partners involved in their plan of care. Collaboration is key for maintaining continuity of care with these children but coordinating the many needs can be challenging. Through in-depth case discussions, this interactive workshop will walk through the many aspects of caring for pediatric patients: medical and clinical care, interdisciplinary collaboration, referral sources, utilizing state coalitions, transitions of care and concurrent care. Through hands-on activities, attendees will have tangible pearls to take back to their team to improve their interdisciplinary team approach to patient care from perinatal to adolescent/young adult.

Outcome 1 - At the completion of this session, participants will be able to: Apply evidence-based care through the evaluation of pediatric cases

Outcome 2 - At the completion of this session, participants will be able to: Identify opportunities for collaboration with community partners and interdisciplinary team members

Outcome 3 - At the completion of this session, participants will be able to: Utilize support systems necessary to facilitate smooth transitions in care for children

Outcome 4 - At the completion of this session, participants will be able to: Implement concurrent care through utilization of a toolkit

Faculty:

- Betsy Hawley, MA Executive Director, Pediatric Palliative Care Coalition
- Melissa Hunt, PharmD Pediatric Clinical Pharmacist, Optum Hospice Pharmacy Services, LLC
- o Jennifer Mangers, CCLS, MS Pediatric Team Manager, JourneyCare
- Elizabeth Rocha, BSN,CHPPN,RN Clinical Director of North Region & Pediatric Director, Hospice of Michigan
- Jessica Sturgeon, HPMT, MT-BC Pediatric Music Therapist, Treasure Coast Hospice



5. Subjects and Contributors for Future Issues of This E-Journal. For upcoming E-Journal issues, we plan to address issues related to Myth Busting. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at ctorkildson@mail.cho.org or christytork@gmail.com; or Ann Fitzsimons at ann@here4U.net. We will work with you!





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