Integrative Therapeutic Interventions in Pediatric Palliative Care


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"Key Concepts"

- A dying child is often highly symptomatic, and providing symptom relief is one of the most compelling domains of pediatric palliative care.
- State of the art in managing pediatric pain and other distressing symptoms at the end of life requires integrating pharmacological with integrative therapeutic interventions.
- Both published case studies and our personal experience strongly endorse integrative treatment modalities, especially imagery, hypnosis, music, aromatherapy, massage, therapeutic/healing touch and acupuncture as effective therapies to control distressing symptoms at children’s end-of-life, and improve their quality of life.

Having a child in palliative care is one of the most anguishing experiences for a family. For pediatric staff there is an added responsibility to provide more than standard medical care during this traumatic time. Going beyond standard medicine, hospices, hospitals and palliative home care services are drawing on complementary and alternative methods, and integrating them into their care to meet the complex physical, emotional and spiritual needs of children and teens who are “living while knowing they are dying” (Kuttner, 2003).

1. Palliative Care – an Introduction

While comprehensive palliative care is the expected standard of care at the end-of-life (Council on Scientific Affairs, 1996; National Quality Forum, 2006), services for the majority of children with life-limiting or terminal conditions fall significantly below those for adults. In the United States and most countries in the developed world, the vast majority of infants, children and teenagers at end-of-life do not have access to multidisciplinary pediatric palliative care services in their community or at their children’s hospital.

Pediatric palliative care (PPC) is for children and teenagers suffering from a life-threatening or life-limiting condition that threatens their survival into adulthood if curative treatments fail. As a result, PPC may last over many years. According to the Association for Children’s Palliative Care (ACT) and the British Royal College of Pediatrics and Child Health (ACT, 2003) PPC “…is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through [disease], death and bereavement.”

Integrative approaches that address symptom management, emotional, spiritual and behavioral issues, and include parents, siblings and school concerns provided by a multi-disciplinary team are now becoming accepted practice. This chapter will examine the current integrative therapeutic interventions for children and teens during the provision of palliative care. Clinical case examples elaborate on the implementation and impact of these approaches.

1.1. Distressing Symptoms at the end-of-life

Five studies looking at prevalence of symptoms in 473 children with malignant and non-malignant diseases reveal that the majority of dying children experience pain, vomiting and dyspnea (Tab. 1). Wolfe et al. (2000a) show in their retrospective study among bereaved parents of 103 cancer patients, that the majority of distressing symptoms were
not treated, and when treated, the therapy was commonly ineffective. A dying child is often highly symptomatic, and providing symptom relief is one of the most compelling domains of pediatric palliative care. Wolfe et al. (2000b) demonstrated that an earlier recognition by both physicians and parents of no realistic chance of cure led to a stronger emphasis on treatment to lessen suffering and integrate palliative care. Consequently, proponents in the field urge that these options be provided early— at best, at diagnosis or early in treatment. As medicine advances, many children are living longer with complex conditions, and the need for ongoing care, support, pain and symptom management increases over longer periods of time.

1.2. Myths
Persisting myths and misconceptions have led to inadequate symptom control in children with a terminal disease. One of the most enduring is the wrongly held belief that in the management of pain and dyspnea, opioids would hasten death and should only be administered as a last resort. It is a common experience of pediatric palliative care teams that administering opioids and/or benzodiazepines, together with comfort care to relieve dyspnea and pain, improves the children’s quality of life. Education about the use of opioids and an understanding that tolerance plus physical dependence does not equal addiction, is an important principle in PPC. Furthermore PPC advocates the provision of comfort care, pain and symptom management concurrently with curative treatments. Families no longer have to opt for one or the other. They can pursue both options, and include integrative approaches to maximize the child’s quality of life.

1.3. Symptom Management
If a child is suffering from pain during the end-of-life, the team providing pediatric palliative care needs to provide prompt and effective pharmacological pain management. Commonly this requires using strong opioids (e.g. morphine, fentanyl, hydromorphone, oxycodone or methadone) by different routes of application (e.g. oral, sublingual, buccal, intranasal, transdermal, intravenous, subcutaneous, rectal, but not intramuscular, as it causes unnecessary pain). The use of adjuvant analgesia may be appropriate (e.g. anticonvulsants, tricyclic antidepressants, benzodiazepines, N-methyl-D-aspartate receptor [NMDA] antagonists, bisphosphonates, antispasmodics, low-dose general anesthetics) and anesthetic or neurosurgical options may be required. (Friedrichsdorf & Kang, 2007).

Today the state of the art in managing pain and other distressing symptoms at the end of life requires integrating pharmacological with integrative treatment modalities. In our experience a pharmacological approach alone will not provide optimal symptom management. Drawing on a combination of physical methods (e.g. massage, physical therapy, cuddles/rocking from family/friends, transcutaneous electrical nerve stimulation [TENS], or hot water bottle or cold pack) with cognitive-behavioral methods (e.g. guided imagery, hypnosis, biofeedback, or abdominal breathing) or modalities such as acupuncture/acupressure, music, expressive art, provides the best possible symptom management.

2. Integrative Therapeutic Interventions in Palliative Care
Complementary therapies aim to restore balance and harmony by working simultaneously on physical, mental, emotional and spiritual needs (McDonald et al. 2006). In British adult hospice and palliative care units, aromatherapy, massage and reflexology are the most popular therapies and are provided in over 90% of these services (Tavares, 2003). Furthermore, it is recognized that interventions that develop
internal coping skills empower children and teens and enhance their quality of life (Sourkes BM, 2000). To date there are no randomized controlled trials (RCT) in pediatric palliative care or RCTs evaluating pharmacological or non-pharmacological treatment strategies for pain and symptom management.

In discussing the frequently used integrative therapeutic interventions in pediatric palliative care, we will report existing pediatric data and present case studies to indicate the mode of application. Since the different CAM methods are described elsewhere in this book, methodology will be briefly mentioned.

2.1 Provider survey on using integrative therapeutic interventions in Pediatric Palliative Care

**Background:** There is a lack of published data about the prevalence of integrative therapeutic intervention usage in pediatric palliative care yet.

**Methods:** The authors sent a questionnaire in November 2007 to the staff of the Pain & Palliative Care and Integrative Medicine Program at the Children’s Hospitals and Clinics of Minnesota in Minneapolis, MN, USA (with a daily census of 80-90 children in palliative care) and Canuck Place in Vancouver, BC, Canada (a free standing, in-patient children’s hospice who cared for 209 patient and outpatients in 2007).

Part 1 surveyed the usage measured by a 5 point Lickert scale of integrative therapeutic interventions: acupuncture, aromatherapy, biofeedback, culturally based healing traditions, energy medicine (Reiki, therapeutic and healing touch), guided imagery, hypnosis, massage, music (played to child), music therapy, and relaxation. It also asked for effectiveness on a 5 point Lickert scale of those methods for the respondent’s palliative patients.

Part 2 inquired, in open-ended questions, about the respondent’s experience of the effectiveness of these integrative therapeutic interventions in treating pain, nausea & vomiting, fatigue, dyspnea, and anxiety in pediatric palliative and end-of-life care.

**Results:** Twenty-eight pediatric palliative care professionals returned the survey (Vancouver n=8, Minneapolis n=20): 14 nurses, 4 physicians, 4 social workers/counselors, 2 psychologists and one advanced nurse practitioner, chaplain, child life specialist, and teacher, respectively. Mean experience in pediatric palliative care was 10.4 years (median 6.5 years).

The most commonly used integrative therapeutic interventions (“often” or “always”) for children and teens in pediatric palliative or end-of-life care at the two centers in Minneapolis and Vancouver were relaxation (64%), guided imagery (46%), energy medicine (39%), and hypnosis (32%). [see Figure 1]

Responses to the open questions regarding integrative therapeutic modalities for specific distressing symptoms, which the respondent witnessed to be “effective” or “very effective” in palliative and end-of-life care of children, are in Table 2.

**Discussion:** The majority of surveyed pediatric palliative care professionals experienced integrative therapeutic interventions as effective in managing distressing end-of-life symptoms in their patients. However, only guided imagery and relaxation are reported to be widely used techniques, furthermore, only a minority of children receive other integrative therapeutic interventions, despite their reported effectiveness.
3. Mind-Body Medicine
Mind-body medicine focuses on intervention strategies that integrate mind processes with body function and experience in order to promote health. For children and teens, these include relaxation, hypnosis, imagery, meditation, yoga, biofeedback, tai chi, qi gong, cognitive-behavioral therapies, group support, autogenic training, and spiritual practices. Mind-body interventions constitute a major portion of the overall use of CAM by the public (NCCAM, 2007). In 2002 mind-body techniques, including relaxation techniques, meditation, guided imagery, biofeedback, and hypnosis, were used for health reasons by about 17 percent and prayer was used by 45 percent of the adult U.S. population (Barnes et al, 2002).

3.1. Imagery
Imagery is a non-intrusive, child-centered, gentle therapeutic modality, which can provide a meaningful alternate experience when the present reality is fraught with pain, fear, fatigue, or physical tension. Imagery can be used in many ways. Two often-used techniques include, focusing directly on the distressing symptom, engaging with it so that it begins to change, or creating a favorite or familiar image that is a more pleasant alternative to the distressing symptom. Imagery is a precursor to hypnosis, and often used as an induction to hypnotic trance in which change can more rapidly occur.

Pediatric Evidence
When used for pain control, imagery works synergistically with analgesics to reduce pain and discomfort (Kuttner & Stutzer, 1995). This modality enables a child to focus attention on a personally meaningful imagery experience and as the imagery becomes more absorbing, the child or teen may dissociate from pain, increase comfort, reduce anxiety, or alter the pain sensations and perceptions (Kuttner 1997; LeBaron & Zeltzer 1984; Zeltzer & LeBaron 1982). For general principles, the book “Mortally Wounded” details the clinical use of imagery to ease a patient's anguish at end of life (Kearney, 1996).

Case Example
Ian was an eight-year-old boy with end stage cancer (rhabdomyosarcoma). He experienced dyspnea during his last week of life. His parents were taught to assist him with guided imagery, which allowed Ian to review and enjoy important events in his life. Together, using a poster board they created a time line, starting with Ian's birth. Ian and his family spent hours each day on this activity. Ian visibly calmed during the sessions, his breathing becoming deeper and more regular. Focusing on his important life events, recreating images and soliciting information from his parents to round out the stories, he created a full and meaningful sense of his own life. Ian died peacefully the day after he completed his full imaginative reminiscing, bringing his own closure and giving his family the comfort of vivid memories of their life together.

3.2 Hypnosis
Hypnosis involves the cultivation of an altered state of awareness, leading to heightened suggestibility that allows for changes in a child’s perception and experience, bypassing conscious effort. In hypnosis the clinician enters the child’s world, engaging the child’s imagination as the agent of change and creating alternate experiences to promote therapeutic change. In trance, the child addresses distressing symptoms utilizing
suggestions by the clinician for altering sensations, perceptions and increasing comfort (Olness & Kohen 1996).

**Pediatric Evidence**

Hypnosis has been used over the last two decades in a number of RCT treatment studies to control pain during invasive medical procedures (e.g. Zeltzer & LeBaron, 1982, Kuttner 1988, Liossi 2002) Zeltzer et al, 2002, in a feasibility study successfully combined acupuncture and hypnosis for 33 children to improve chronic pain. Acupuncture was according to Traditional Chinese Medicine, and hypnosis comprised of muscle relaxation, the suggestion of going to a safe or favourite place, followed by imagery designed to strengthen the child’s sense of mastery in which the child’s brain became the cockpit of her airplane.

**Case Example 1**

Ann was a 17-year-old with a terminal prognosis of lung and abdominal metastases following a malignant bone tumor (osteosarcoma). She had three sessions to teach her self-hypnosis to reduce her anxiety and chronic pain before a radical pelvicectomy for palliation for unremitting bone pain. The hospice chaplain conducted a ceremony with Ann and her family before the amputation to acknowledge the impending loss of her leg. After surgery she experienced phantom limb pain and found self-hypnosis insufficient.

The therapist asked Ann for permission to talk to the part of her brain that perceives pain from her leg, and gave the suggestion that she did not need to listen to this part of the session if she did not want to. This was a confusing concept for Ann and helped to facilitate her trance. Using a hand levitation induction with the creation of a safe place image, the therapist said:

“I’m addressing the part of your brain that sends and receives messages about discomfort and pain from your right leg. You do not need to worry about not getting messages from the right leg anymore. The right leg is in a safe place where there is not any discomfort or pain. You can shift your attention to the rest of your body and know that the right leg is safe. It’s not part of your job anymore to monitor the right leg.”

This message was repeated several times interspersed with messages about how she could now allow herself to relax and be pain free. She experienced a marked decrease of phantom limb pain after this session. Four weeks later she was readmitted to remove lung metastases, and after surgery had a severe pain crisis with a return of phantom limb pain. Another hypnosis session was held. Ann was informed that her brain and neural pathways had been hyper-activated by the pain crisis, and we just needed to remind the part of the brain that had monitored the right leg that it could once again rest and not send messages to the right leg. Her phantom limb pain again subsided to mild and infrequent.

**Case example 2**

Katie was a 12-year-old girl with a rare progressive neurological disease, with its onset a year earlier. Previously diagnosed with Asperger’s disorder, she was cognitively intact but was losing muscle control requiring assistance with her personal care. She started experiencing dyspnea and used an opioid and a benzodiazepine medication to ease this symptom. The social worker had met Katie at her home and spent time with her parents discussing their coping of Katie’s terminal diagnosis and their focus on providing comfort care for her. On the next visit she found Katie terrified, lying on the couch in the den
experiencing breathlessness. Her mother had given Katie morphine for the dyspnea and was on her knees talking to Katie trying to reassure her. The therapist decided to coach the mother in calming Katie, who was whispering, “I can't breathe!” The therapist knelt beside the mother and talking to both mother and child in a calm voice said:

“Katie, I want to help you and your mother breathe. Katie, look into your mother’s eyes, she is going to help you breath. Joan (mother) Breathe nice and easy and keep looking into Katie eyes. Katie, you can now breathe with your mother. She can help you while your medicine starts to work. Your mother has you.”

The mother had a hand on each of Katie’s arms. Katie quickly slowed her respirations and started to breath with her mother. Her panic quickly subsided. There was no need for an induction, as Katie terrified, was already in a trance. The therapist became directive, and drawing upon their healthy attachment, restructured the experience for both mother and child. The mother naturally joined with her child to help her to regulate her anxiety and her breathing. With this coaching, Katie’s mother was able to calm and prevent panic as Katie became weaker and approached death.

3.3. Biofeedback
Biofeedback is a self-regulatory skill that uses electronic or electromechanical equipment to measure then feedback information about physiologic functions, which the child uses to gain control over these responses in a desired direction. The functions include, heartbeat, blood pressure, and muscle tension. The feedback is provided in auditory, visual and multimedia game formats that appeal to children. There are no published adult RCT or pediatric case reports using biofeedback in palliative care.

Case Example
Ravi, a 16-year-old with terminal cancer (recurrent germ cell tumor and myelodysplastic syndrome) with recurrent chest pain at the site of tumor, leg pain of unknown cause, and recurrent nausea associated with anxiety. He took morphine doses for chest pain, resulting in drowsiness and additional nausea. His coping pattern in the hospital consisted of withdrawal, isolation, little physical activity and keeping his room dark. Ravi denied emotional distress, and when not withdrawn, he frequently used humor. Although Ravi had met psychosocial and CAM providers in the hospital, he reported “those things do not work on me.” At home, Ravi met the team psychologist, and agreed to meet again in the outpatient pain and palliative clinic.

Ravi had 13 visits over four months with the psychologist, focused on rapport, emotional support, processing medical events, and address symptoms using relaxation strategies. Initially he reported little relief with guided imagery or diaphragmatic breathing. He tried the biofeedback game on a couple of occasions, then participated in self-hypnosis and relaxation, ultimately acknowledging their benefit and initiating use on his own. The biofeedback program was based on heart rate variability, and Ravi’s ability to control heart rate with breathing. It was explained that the better he became at controlling his breathing, the more likely he could control his pain. This was illustrated concretely on the computer screen with changing color patterns as well as transforming images (e.g., the higher the hot air balloon, the better the performance). Ravi said that he saw the biofeedback as a challenge and wanted to get good at it. By coupling the physical challenge with suggestion of pleasant memories or feelings, Ravi enjoyed the activity and challenged himself to evoke the relaxation response. The biofeedback program, with
its technology and entertainment provided him with a personally acceptable technique suiting his age, personality and avoidant coping style.

3.4. Yoga
Yoga is a 5,000-year-old practice from Ayurvedic medicine that combines breathing exercises, physical postures, and meditation. It is intended to calm the nervous system and balance the body, mind, and spirit (NCCAM, 2007). Experience suggests that yoga can be of benefit during palliation if the child or teen is already familiar with the practice, has used diaphragmatic breathing, or has favourite postures (asanas) that ease pain, reduce anxiety or discomfort, such as the ‘child’s pose’ or ‘cat stretch’.

Pediatric evidence
While there are no published pediatric case reports about the use of yoga in palliative care, yoga has been studied in a RCT to treat adolescents with recurrent abdominal pain and irritable bowel syndrome and found to significantly lower functional disability, reduce anxiety and hold promise for reducing GI symptoms (Kuttner et al, 2006).

3.5. Music
Music has been used for centuries to soothe distress. Defined as an intentional auditory stimulus, it has organized elements including melody, rhythm, harmony, timbre, form and style, (Kemper & Danhauer 2005), Repetitive listening allows the listener to identify and predict sounds (Standley JM, 2002), and is thought to help reorganize and reregulate the nervous system, improving mood.

Pediatric Evidence
There is evidence that classical music and lullabies among premature infants decreases distressed behavior and episodes of oxygen desaturation and increase weight gain and non-nutritive sucking. (Caine 1991; Collins 1991; Standley 2002; Standley 1998; Standley & Moore 1995) The results from a recent Italian prospective RCT found that pediatric patients (4-13 years) exposed to music during venipunctures demonstrated significantly lower distress and pain intensity in the music group compared with the control group before, during, and after blood sampling (Caprilli et al, 2007). Songs and music performed by “professional” musicians, the authors concluded, have a beneficial effect in reducing distress before, during, and after blood tests and that the presence of musicians has a minor, but yet significant, effect on needle insertion pain. A Norwegian case series with four children with advanced cancer (two of them with terminal disease progression) showed that music therapy changed the children from passive recipients of care to being socially active (Aasgaard, 2001). Music therapy improves the quality of life (QoL) at the end-of-life and can ease communication between child and family.

Case Example 1
John was a 2-year-old with arthrogryposis and brain stem lesion resulting in muscle spasticity with extreme muscle weakness. He had poor chest wall expansion for respiration with compromised perfusion. For his first 8 months of life he did not move his skeletal muscles at all. As he grew older he began to move tentatively with great effort. His parents played music for him from birth and sang songs to him daily. They noticed that his breathing regulated and began to go in sync with the musical rhythms. He relaxed and his color improved... By age two he had not yet moved his entire body in a coordinated fashion, but now began to move his arms and legs. One day as he lay on one end of the living room floor on a blanket, his father put a new LP on the stereo: Keith Jarrett’s “The Köln Concert.” The speakers were on the far end of the living room. John
rolled across the floor until he reached the point exactly midway between the speakers. He stayed there listening to the entire jazz piano concert. John received music therapy from ages 3-5, enjoying working on pronation and supination of his wrists playing percussion instruments, and learning to direct music. Years later now twenty-two-year-old, John plays percussion with a band, researches and catalogues music as a hobby, and shares his love of music with friends and college classmates.

**Case Example 2**

Three-year-old Angela was actively dying at home. Her cancer (neuroblastoma) had relapsed, and she was being treated for severe dyspnea. With parents at her side, she showed signs of restlessness and anxiety as her breathing became more difficult. Oxygen was not improving Angela’s dyspnea. When the hospice chaplain arrived, he asked what Angela enjoyed most. When they told him she loved music, he suggested they sing some of her favorite songs. With the familiar music and her parents’ continued closeness, Angela relaxed and her breathing calmed considerably. Music was an important part of her last hours, and her parents loved being able to provide this comfort for her.

### 3.6. Art

Art activities have been shown to be particularly helpful for children and teens to express their feelings and difficult experiences in a child-centred manner (Kuttner, 2003). Often children don’t have the vocabulary to express their feelings, or the feelings are too painful or awkward to discuss (Devlin 2006). Art provides a non-verbal expressive medium to convey these complex, confusing emotions and experiences in a way that is personally satisfying.

**Pediatric Evidence**

Case reports show the effective use of art therapy in facilitating expressive communication and coming to terms with grief both for a lost family member and for children affected with an incurable disease (Devlin 2006, Devlin 1996). Sourkes (2007) shows the clinical value, honesty and poignancy of children’s drawings, graphically depicting their psychological experience as they struggle with a life-threatening illness.

### 3.7. Virtual Reality

Virtual reality is a recent technology that fully absorbs and stimulates the human senses giving the feeling of being in another world. As an intervention with adult cancer patients it decreased fatigue and emesis (Oyama 2000). With children it is a popular form of play experience.

**Pediatric evidence**

Since 2005 the investigative clinical research using virtual reality has accelerated, bringing new evidence of its therapeutic potential for the alleviation of pain as a distraction technique during procedural pain (Gold et al, 2006; Lange et al, 2006; Das et al, 2005; Magora et al, 2005). As yet here are no published pediatric case reports about the use of virtual reality in palliative care, although some hospices use these devices for play and diversion with children who are still mobile.

### 3.8. Multisensory environment (Snoezelen)

Hospices have adopted the word “Snoezelen” from the Dutch meaning sniffling and dozing to describe a multisensory room supplied with changing coloured lights across the walls, music, aroma, tactile stimulation, and taste. These sensory changes create a
dusky, attractively lit room, providing a soothing environment for ailing children. (Schofield 2003) Many freestanding inpatient children’s hospices incorporate a multisensory room on site. As yet, there are no published pediatric case reports about the use of a multisensory environment in palliative care.

3.9 Aromatherapy
Hundreds of receptor cells have been identified in the nasal passages which relay smell to the brain (Balacs 1992). Essential oils are highly concentrated non-oily, fragrant substances extracted from plants by distillation, which evaporates readily. Aromatherapy is thought to work by promoting the release of neurotransmitters once the nasal receptor cells are stimulated by these distilled fragrants (Kyle 2006). Sandalwood oil was effective in reducing anxiety (Kyle 2006). In the United Kingdom, aromatherapy combined with massage is the most widely used complementary therapy in nursing practice (Macmillan Cancer Relief 2002; Rankin-Box 1997).

Pediatric Evidence
Styles reports that aromatherapy was beneficial in managing the distressing symptoms for 20 children with HIV disease in palliative care. (Styles, 1997)

Case Example 1
Thirteen-year-old Jasmine received aggressive chemotherapy for osteosarcoma in her pelvis. Her nausea was severe, subsiding only with scheduled dosing of diphenhydramine, lorazepam, and ondansetron. Jasmine had much difficulty with the sedating effects of the antihistamine and benzodiazepine. She agreed to try aromatherapy. Essential oil of ginger, considered to have beneficial affects on the GI tract was introduced using a diffuser in her hospital room. Jasmine responded beautifully. Diphenhydramine and lorazepam became less necessary to control nausea. Together with diffused aromatic ginger, ondansetron became Jasmine’s only scheduled medication for nausea.

Case Example 2
When Marta, a six-year-old with a retinoblastoma, was introduced to opioids for localized pain, she experienced urinary retention. Marta had become increasingly fearful as she underwent treatments and procedures. It was clear to her care providers that urinary catheterization, another invasive procedure, would be difficult for Marta to tolerate. Two drops of oil of peppermint, known to relax the urinary sphincters was dropped into the “hat” placed in the commode, and Marta was able to urinate without catheterization.

4. Manipulative and body-based practices
Manipulative and body-based practices is a heterogeneous group of integrative interventions and therapies, which include chiropractic and osteopathic manipulation, massage therapy, Tui Na, reflexology, rolfing, Bowen technique, Trager bodywork, Alexander technique, Feldenkrais method, and a host of others (NCCAM, 2007).

4.1 Massage
Massage includes pressing, rubbing, and moving muscles and other soft body tissues primarily using the hands and fingers. The aim is to increase blood-flow and oxygen to the massaged area (NCCAM, 2007). Massage was helpful reducing anxiety and enhancing hope in cancer patients (Downer et al 1994, Wilkinson et al, 1999). Massage Therapy in a pediatric hospice setting can have significantly unique demands, and
therefore the term massage can be confusing. Hence the terminology is sometimes being changed into “Integrative Touch” or “Compassionate Touch”. (Beider et al, 2007)

Pediatric evidence
While there are no published pediatric case reports about the use of massage in palliative care, massage has been effective in ameliorating pain and distress in infants (Fields, 2002).

Case Example
Amy, a 17 year-old girl diagnosed with metastasized colon cancer, had a tumultuous psychosocial history of abandonment by her biologic mother and abuse by an adoptive parent. When she was diagnosed with terminal disease her newly retired paternal grandparents offered their home to her. In addition to psychosocial supports and medications for pain management, home-based massage therapy was offered, at first shyly refused. With encouragement Amy accepted reporting much comfort and relief from these sessions. For her, massage therapy provided added benefits. Human touch was especially helpful in view of her troubled background with few close positive human interactions. She also had opportunities to relax and talk about her concerns with the therapist. Medically, massage assisted Amy with circulatory problems that were developing because of rapid tumor growth and decreased activity. Amy reported better sleep quality and less muscle tightness and pain after she began regular massage therapy sessions, and her caregivers noted an overall improvement in her anxiety level.

4.2 Reflexology
Reflexology is the process of gentle, but firm manipulations of the feet and/or hands to stimulate specific reflex points of the body. This is based on the principle that there are reflexes running along the body, which terminate in the feet and the hands, and that the body’s organs and systems are represented on the skin’s surface. (Hodgson 2000; Norman & Cowan 1989). First documents describing the use of reflexology are dated to 2300 BC in Egypt (Lockett 1992). A Japanese study of 20 terminally ill cancer patients showed that combined modality treatment consisting of aromatherapy, footsoak, and reflexology was found effective for alleviating fatigue at end-of-life (Kohara et al, 2004). There are no pediatric case reports on the use of reflexology in palliative care.

5. Energy Medicine
The National Center for Complementary and Alternative Medicine describes Energy Medicine as:

“…based on the concept that human beings are infused with a subtle form of energy. Vital energy is believed to flow throughout the material human body, but it has not been unequivocally measured by means of conventional instrumentation....Herbal medicine, acupuncture, acupressure, moxibustion, and cupping, for example, are all believed to act by correcting imbalances in the internal biofield, such as by restoring the flow of qi through meridians to reinstate health.... Examples of practices that focus on these energy fields include:

- Acupuncture and Acupressure
• Reiki and Johrei (both of Japanese origin)

• Qi gong (a Chinese practice)

• Healing touch/ Therapeutic touch in which the therapist identifies imbalances and corrects a client's energy by passing his or her hands over the patient

• Intercessory prayer, in which a person intercedes through prayer on behalf of another

These approaches are among the most controversial of CAM practices because neither the external energy fields nor their therapeutic effects have as yet been demonstrated convincingly by any biophysical means.” (NCCAM, 2007) Despite that they are increasingly practiced in Australia, Europe and North America, and Therapeutic Touch practiced by nurses in North American hospitals gained considerable credibility.

5.1. Acupuncture
Acupuncture includes a family of procedures originating in traditional Chinese medicine. Acupuncture is the stimulation of specific point on the body by a variety of techniques, including the insertion of thin metal needles through the skin, to remove blockages in the flow of qi and restore and maintain health (NCCAM, 2007).

Traditional Chinese Medicine (TCM) approaches the child in a holistic manner, recognizing the inseparable relationship of the body mind and spirit (Flaws 1997). Traditional Chinese Medicine theory believes when a person is in a state of health, Qi or life energy is flowing smoothly through meridian or pathways that connect all systems of the human being, physical, mental and spiritual (Kaptchuk 1983). When a child suffers from pain, associated symptoms, such as anxiety, stress, depression, insomnia, loss of appetite are also treated. Pain is considered a symptom of the stagnation of the flow of life energy or Qi. TCM treatments aim to restore a balance of these systems and the smooth flow of life energy in a coherent approach. (Maciocia, 1994) Improving quality of life is the main objective of Traditional Chinese Medicine treatment. There are no published adult RCTs or pediatric case reports about the use of acupuncture in palliative care.

Case Example
Eight-year old Corey’s initial complaints about back and leg pain, started innocently with progressive difficulty walking. An extensive medical workup diagnosed Neuroblastoma in his spinal cord. He had multiple surgeries and was treated with multiple trials of chemotherapy, conventional spine and brain radiation, gamma knife, proton beam stereotactic radiosurgery and experimental drug protocols.

Two years later, with uncontrollable tumor spread, escalating pain and failing neurological function, his medical team met with his family to discuss discontinuation of therapies including OT and PT. Corey had lost the ability to walk and became incontinent for bowel and bladder, and his death was thought to be imminent. With a palliative treatment plan in effect, Corey was discharged home with an intravenous opioid (fentanyl) infusion pump. His neurosurgeons, having little to offer with standard western support, referred him for Traditional Chinese Medicine (TCM) to salvage some quality of life (QOL).
Corey’s mother was skeptical that Chinese Medicine offered her son any hope of relief when western medicine had failed. But on the advice of her son’s neurosurgeon, she took him to the TCM clinic. On his initial visit, Corey was sitting in the waiting room, banging his head against the wall crying and moaning that his leg pain was unbearable. His fentanyl infusion pump had been increased to deliver 975 mcg per hour, he had not slept in 3 days and had been crying uncontrollably. Acupuncture began with placing two 40 gauge acupuncture needles (the width of a strand of hair) in appropriate points, with immediate effect. Corey fell asleep within 2 minutes for the first time in days and continued to sleep for 90 minutes. He awoke reporting that his pain was significantly lower, told his mom he was hungry and wanted to stop at Taco Bell. Calmed, he asked if he could return to the clinic. We scheduled Corey for treatment twice a week. Corey received acupuncture, acupressure, Tui Na medical massage, moxibustion, herbal therapy and seed patch therapy. All were aimed at improving QOL.

Corey’s dose of opioid analgesia was not providing adequate pain relief and he had severe anxiety attacks, terrified that his pain was uncontrollable, insomnia, anorexia and depression. Corey was treated with the National Acupuncture Detoxification Association (NADA) protocol, a five point auricular (ear) acupuncture treatment, utilized in the treatment of addiction, tolerance and pain. (Oleson, 2002) Corey was also treated with main meridian acupuncture, acupressure and moxibustion (Scott, 1986). Corey responded wonderfully. After 6 acupuncture treatments his fentanyl dose was reduced to less than 200 mcg per hour. By week five he was rotated to 50 mcg/hour fentanyl patches. Corey experienced significant improvement in quality of life, participating in daily activities, interacting with family and most significantly his pain was well-controlled. At the beginning of each visit he would share these activities and joyfully recount playing games or funny episodes of a Sponge bob cartoon. He was sleeping well and enjoying meals. With his QOL improving, the scope of his TCM treatments expanded to address his neurological deficits such as weakness and loss of bowel and bladder control. Corey improved so much that his physicians recommended that physical and occupational therapy be reinitiated. By month 4 of treatment Corey was able to stand and walk down the hall wearing leg braces.

Corey’s “wish” was to attend 3rd grade, a fantasy previously impossible. Due to his illness, he had spent little time in school with other children. He wanted to be like other 8-year-olds and go to school. He was so excited preparing for his first day that he brought his new school backpack to the clinic to share. Corey started 3rd grade. He attended school for the first half of the year until a reoccurrence of spinal tumors led to his death. Corey passed peacefully with his family and loved ones by his side.

When the parent or caregiver is also supported with treatment and their stress is addressed, the child can receive greater benefits from their own treatments (Jarret, 1998). Over the course of Corey’s 17 months of treatment, his mother also received acupuncture and herbal therapy to support her through a most difficult time. Although his diagnosis never changed, he lived many months longer than expected. During this time, he enjoyed a dramatically improved quality of life.

5.2 Shiatsu

Shiatsu is a Japanese body therapy, developed from an ancient form of massage, that works on the energetic pathways (meridians) and points of access (tsubos) in order to harmonize the energy flow (qi). The philosophy is rooted in the theory of traditional
Chinese medicine (TCM), which holds that energy imbalances cause ill health and that by rebalancing the qi, relief may be experienced. (Cheesman et al 2001) No pediatric case reports about the use of shiatsu in palliative care have been published.

5.3 Energy Healing
Energy healing is predicated on a structured system of dynamic energy surrounding and penetrating the human body; auras and chakras (energy centers) within individuals and from the Universal Energy Field. This energy system can be impacted, influenced, balanced, and strengthened or weakened by the person or other people. People can be trained to balance, strengthen, and repair their own and others’ energy systems. A well functioning energy system allows the human body’s own self-healing mechanisms to function at optimal levels. At this time there are no published adult RCTs or pediatric case reports about the use of energy healing in palliative care. However Reiki and Therapeutic Touch are frequently use in hospices and pediatric hospitals to alleviate pain and soothe and settle distressed children.

Case example 1
Lulu, a young adolescent Hispanic American girl was diagnosed with leukodystrophy and global developmental delay. She was gradually losing her physical and cognitive abilities, and at the time we knew her was only able to speak in short sentences. She crawled around in a hopping rabbit sort of fashion. She was a physically beautiful girl with a very loving spirit, and an innocence that people often referred to as angelic. Her parents called saying that they were upset because she was “seeing things.” Speaking with mom at the next visit she explained that she would walk into Lulu’s room and she would be talking and playing, but there was no-one else there. This upset both parents, as they worried Lulu was losing her mind. When we asked Lulu about the experience, she said that she had 2 or 3 playmates who visited regularly, and was surprised her mom could not see them. She said they stayed a while and then would go away, but they always said they would be back to play some more. She was happy to have their visits, and seemed absolutely comfortable with it all. After several reports, we began to postulate that friends “from the other side” were indeed visiting, so that when Lulu did die, she would have playmates in the next life. Lulu’s mother was further comforted when Lulu’s energy system, assessed during healing touch sessions, showed an increasing brightness and openness of Lulu’s spiritual chakras. This provided a new conceptual framework for her, and “normalized” the experience for the family, allowing them to continue to relate to Lulu as they always had. They were no longer afraid.

Case example 2 (Craniosacral Therapy)
Greg was an infant with a genetically inherited terminal neuro-degenerative disease. He had a five-year-old healthy sister and parents in their late 20’s, who had previously lost a baby to the same disease. They were well-educated European Americans who were pro-environment and health-food oriented people. Caring for Greg was a 24-hour job because of his neuroirritability. He needed to be held constantly, and even then his high-pitched cries went on for hours. Various medications were tried to soothe his hyperactive nervous system and decreased his sensitivity, but nothing worked until craniosacral therapy was provided by a trained nurse. This gentle technique, physically holding the baby’s cranium and slowly ‘unwinding” tension, calmed him, and this effect lasted for hours, sometimes for days. It was a miracle to the family. At last they could all have some good quality of life. Greg’s mom became trained and was able to continue daily craniosacral therapy with Greg. He lived a much calmer and more peaceful life with his family until he died in his parents’ arms.
5.4. Rituals/Prayer

Case Example
When Britta, a teenage patient with metastasized osteosarcoma of the left leg was facing an above-the-knee palliative amputation, she became anxious and withdrawn. Her family was unable to comfort her with explanations about the efficacy of treatment. The team chaplain offered to do a ritual leg blessing for Britta. In the session, Britta’s upcoming loss was acknowledged, and she was given the opportunity to reflect on the blessing her leg had been to her, how it had served her, and how its sacrifice was now provided her with the gift of improved quality of life. After this session Britta approached surgery with greater acceptance in the face of her devastating loss.

6. Culturally-based Healing Traditions
Pediatric palliative care needs to be provided within families’ spiritual-cultural boundaries. First-generation immigrants may frequently adhere to spiritual and cultural practices, and at a time of imminent loss may be hesitant to embrace Western medical practices. It is paramount for the palliative care team to learn about their beliefs and practices, and where possible include rituals and practices important to the family and their culture.

Case Example
Chue was a 10-year-old born in the US with parents who were first generation immigrants, highly identified with their traditional Hmong culture. Chue had a brainstem glioma and when referred to palliative care was given a prognosis of less than a few months. He was aspirating significantly with a series of secondary pneumonias. Mom was encouraged not to feed him as this posed aspiration risks as his capacity to suck/swallow would continue to deteriorate. He was fairly non-verbal when we met him, but engaged actively with his parents and three siblings through vocalizations and eye contact.

It was important to his mother to feed him orally, though this took her many hours. She reported it was not a problem, and related he did better with the special way she took care to feed him. She provided Chue with a tea or soup made of traditional herbal medicines, sent to her by a friend in Laos. She brewed/cooked these dried herbs in a large pot water, and spooned the traditional medicine into his mouth in a painstaking way. She couldn’t say what was in it, and eventually the medical care team decided not to delve further as there appeared to be no drug interactions.

Chue’s condition progressed at a much slower rate than had been anticipated. He had no further pneumonias, and though he aspirated, he seemed pretty stable. Mom however, became distressed and agitated. After a few visits and with effort to understand her upset she disclosed that the family had no money to pay the shaman to perform the essential traditional rituals and she was fearful about what would happen to her son’s spirit. She would not disclose what these rituals were, only that money was needed to pay the shaman to obtain the chicken and other materials for the rituals.

Through philanthropic funds in our program, the family was given the $200 for this ritual. They contracted and held the ceremony privately in accordance with their traditions. We were not given information about it. After the ritual, mom’s demeanor and mood seemed lighter, and she reported that she was deeply relieved knowing they had fulfilled their
obligations to their son’s spirit, and whatever happened, he would be OK. Chue outlived the original prognosis by over a year, and was comfortable and apparently happy with is mother’s care. He required very little pain medicine throughout his last year of life.

7. Summary
Pediatric palliative care is an emerging new field of care for children and teens with life-limiting and life threatening illness. It draws on all commonly used western-based medical treatments as well as complementary and alternative treatments to attain the best patient comfort and ease at end of life. While there are no randomized controlled trials evaluating the use of these integrative therapeutic interventions – interestingly the same holds true for pharmacologic treatments in pediatric palliative care. Both published case studies and our personal experience strongly endorse integrative treatment modalities, especially imagery, hypnosis, music, aromatherapy, massage, therapeutic /healing touch and acupuncture as effective therapies to control distressing symptoms at children’s end-of-life, and improve their quality of life. Parents and other caregivers can be trained in some of these methods empowering their capacity to provide care. Participation in a child’s end-of-life care lessens bereavement complications in families, and promotes parents’ ability to come to terms with the loss of their child.

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Table 1
Symptom prevalence of children with malignant and non-malignant life-limiting conditions during their end-of-life period.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Dangel, 2001 (Poland) n = 160</th>
<th>Drake, 2003 (Australia) n = 30</th>
<th>Goldman, 2000 (UK) n = 152</th>
<th>Hongo, 2003 (Japan) n = 28</th>
<th>Wolfe, 2000a (USA) n = 103</th>
<th>Total n = 473</th>
<th>Prevalence in %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>134</td>
<td>16</td>
<td>140</td>
<td>21</td>
<td>84</td>
<td>395</td>
<td>84</td>
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<tr>
<td>Fatigue</td>
<td>86</td>
<td>21</td>
<td>79</td>
<td>20</td>
<td>100</td>
<td>297</td>
<td>63</td>
</tr>
<tr>
<td>Vomiting</td>
<td>101</td>
<td>12</td>
<td>87</td>
<td>16</td>
<td>58</td>
<td>274</td>
<td>58</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>80</td>
<td>12</td>
<td>62</td>
<td>23</td>
<td>84</td>
<td>261</td>
<td>55</td>
</tr>
<tr>
<td>Constipation</td>
<td>94</td>
<td>8</td>
<td>58</td>
<td>13</td>
<td>51</td>
<td>224</td>
<td>47</td>
</tr>
</tbody>
</table>

Table 2
Effectiveness of integrative therapeutic interventions in pediatric palliative and end-of-life care for distressing symptoms as experienced by 24 pediatric palliative care professionals

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Integrative Modality</th>
<th>“Effective” or “Very effective”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Guided Imagery</td>
<td>54 %</td>
</tr>
<tr>
<td></td>
<td>Massage</td>
<td>54 %</td>
</tr>
<tr>
<td></td>
<td>Hypnosis</td>
<td>42 %</td>
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<tr>
<td></td>
<td>Acupuncture</td>
<td>29 %</td>
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<tr>
<td></td>
<td>Biofeedback</td>
<td>25 %</td>
</tr>
<tr>
<td></td>
<td>Energy work (e.g. Reiki, healing touch)</td>
<td>25 %</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Aromatherapy</td>
<td>29 %</td>
</tr>
<tr>
<td></td>
<td>Music</td>
<td>29 %</td>
</tr>
<tr>
<td></td>
<td>Energy work (Reiki, healing touch)</td>
<td>29 %</td>
</tr>
<tr>
<td>Nausea &amp; vomiting</td>
<td>Aromatherapy</td>
<td>54 %</td>
</tr>
<tr>
<td></td>
<td>Guided Imagery</td>
<td>29 %</td>
</tr>
<tr>
<td></td>
<td>Hypnosis</td>
<td>29 %</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Guided Imagery</td>
<td>38 %</td>
</tr>
<tr>
<td></td>
<td>Relaxation</td>
<td>33 %</td>
</tr>
<tr>
<td></td>
<td>Hypnosis</td>
<td>25 %</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Guided Imagery</td>
<td>63 %</td>
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<td></td>
<td>Hypnosis</td>
<td>46 %</td>
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<tr>
<td></td>
<td>Relaxation</td>
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<tr>
<td></td>
<td>Massage</td>
<td>42 %</td>
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<tr>
<td></td>
<td>Music</td>
<td>42 %</td>
</tr>
<tr>
<td></td>
<td>Aromatherapy</td>
<td>33 %</td>
</tr>
<tr>
<td></td>
<td>Energy work (Reiki, healing touch)</td>
<td>25 %</td>
</tr>
</tbody>
</table>
Figure 1
Responses from 28 pediatric palliative care professionals regarding the subjectively perceived effectiveness of integrative therapeutic interventions in pediatric palliative care, in daily practice.
References


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