

Integration of hypnosis into pediatric palliative care

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Abstract: At least 8 million children would need specialized pediatric palliative care (PPC) services annually worldwide, and of the more than 42,000 children and teenagers dying annually in the United States, at least 15,000 children would require PPC. Unfortunately, even in resource-rich countries the majority of children dying from serious advanced illnesses are suffering from unrelieved, distressing symptoms such as pain, dyspnea, nausea, vomiting, and anxiety. State of the art treatment and prevention of those symptoms requires employing multi-modal therapies, commonly including pharmacology, rehabilitation, procedural intervention, psychology, and integrative modalities. This article describes the current practice of integrating hypnosis into advanced pain and symptom management of children with serious illness. Three case reports of children living with a life-limiting condition exemplify the effective use of this clinical modality to decrease distressing symptoms and suffering. Hypnosis for pediatric patients experiencing a life-limiting disease not only provides an integral part of advanced symptom management, but also supports children dealing with loss and anticipatory loss, sustains and enhances hope and helps children and adolescents live fully, making every moment count, until death.

Keywords: Pediatric palliative care (PPC); hypnosis; integrative medicine; child; hypnotherapy

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“There were heaps of little computers, and each one was operated by, like, little people, and each one was operated by a different person. You can actually tell them if you want the pain to go down or the nausea to go down, or whatever...”—response of an 11-year-old girl with leukemia during her end-of-life period when asked what it was like traveling to her own brain while in hypnotic trance.

Introduction

This section will offer an introduction into pediatric palliative care (PPC), followed by the importance of addressing distressing symptoms at end-of-life in children, and finally describes hypnosis in pediatrics.

Pediatric palliative care

At least 20 million children worldwide would benefit from PPC annually, and more than 8 million children would need specialized PPC services (1). In 2013 a total of 42,328 children 0–19 years died in the United States, more than 55% [23,440] of them infants younger than 1 year (2). The leading causes of pediatric deaths include accidents (7,645 children), suicide [2,143], and homicide [2,021]. Leading life-limiting conditions, the emphasis of this article, include congenital malformations and chromosomal abnormalities [5,740] followed by malignancies [1,850]. Conservative estimates suggest that more than 15,000 pediatric patients annually would benefit from PPC in the

United States alone (3).

PPC is considered state of the art specialized medical care for children with serious illness. It is advanced care focused both upon the relief of distressing symptoms and the stress of a life-limiting disease. The provision of PPC is appropriate at any age and at any stage, together with curative treatment. The primary goal is to improve the quality of life for the child and his or her family by thoughtfully matching treatments to patient goals.

In the words of an ill child, *“Palliative care no longer means helping children die well, it means helping children and their families to live well, and then, when the time is certain, to help them die gently.”* (Mattie Stepanek, 1990–2007).

Adult evidence obtained through randomized controlled trials (RCTs) that the integration of palliative care improves the quality of life and prolongs life (4,5) also has been described in pediatric case reports (6-8). High-quality PPC for children with serious illnesses is now an expected standard of medicine. In addition to providing advanced clinical care, PPC services are also cost-effective, although arguably not a single clinician worldwide provides PPC “to save money”, but rather, because this branch of medicine provides superior clinical care to children with advanced serious illnesses (9-12). However, there remain significant barriers to achieving optimal care. These barriers are related to lack of formal education, reimbursement issues, the emotional impact of caring for a dying child, and most importantly the lack of interdisciplinary PPC teams with sufficient staffing (13).

Distressing symptoms in PPC

Pediatric patients enrolled into PPC programs have an average of nine distressing symptoms (14), and unfortunately in children with advanced serious illness, e.g., cancer, the majority of those symptoms (including, for example, pain, dyspnea and nausea/vomiting) are not treated during the end-of-life period, and when treated, the therapy is commonly ineffective (15-19). Parents of children with malignancy who received PPC reported that the children experienced less distress from pain, dyspnea and anxiety during the end-of-life period (18). In addition, children and teenagers who received pediatric palliative home care were more likely to have fun and to experience events that added meaning to life (19). Furthermore, families who received PPC services report improved communication (20) and children receiving PPC experienced shorter hospitalizations

and fewer emergency department visits (21). Advanced pain and symptom management for children with serious illness requires employing multiple pharmacological agents, interventions, rehabilitation, psychological and integrative therapies. Together these act synergistically to achieve more effective pediatric pain and symptom control with fewer side effects than a single medication or modality (22-27).

Hypnosis in pediatrics

Hypnosis has been variably defined (28-31) but may be best understood as an alternative state of awareness which we are all in and out of all day long. It is very useful for clinicians to understand and think of hypnosis as a skill (not a pill!) set which all people (and perhaps especially children) have, which they can be helped to recognize, acknowledge, and build upon for their own benefit (32). In this sense there are two kinds of hypnosis, those which are spontaneous and occur in each of us and all around us all day, and those which we invite, “induce”, initiate for purposes of accomplishing a specific goal or solving a problem of some kind. Examples of spontaneous hypnosis/hypnotic behaviors are easily noted if only we (as clinicians, parents) will pay attention to them and learn to help others notice, and learn to strengthen and utilize them (clinically). We are “in hypnosis” or “doing” (self) hypnosis whenever we narrow our focus and concentrate on something with an intention or purpose to make a change. We are in hypnosis, a hypnotic state, a state of narrowed focus on, for example, studying for a test, shooting a free throw in basketball, rehearsing a role in a play, practicing a musical instrument, focusing on the right foot (or some other part of the body) in order to decrease focus on an injured left foot or hand, imagining how things will be in 2 weeks, 2 months, 2 years, or remembering a favorite birthday party or other happy time from our recent or more distant past. Beyond these spontaneous, every day experiences the “other” form of hypnosis is when we are invited or coached or guided in our hypnosis with the expressed, explicit purpose of solving a problem, eliminating a habit, reducing a discomfort, coping with stress of some kind, falling asleep more easily, etc. In both spontaneous and so-called “induced” or invited/guided/facilitated hypnosis what is most operative and most important is the cultivation of that state of imagination and alternative awareness, characterized by heightened suggestibility toward developing the desired change in an individual’s perception and experience. 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 (33). In hypnosis the clinician becomes aware of and facilitates the child's utilization of their imagination, engaging the child's imagination as the agent of change and creating alternate experiences to promote therapeutic change (29,34). In trance, the child addresses distressing symptoms utilizing suggestions by the clinician for altering sensations, perceptions and increasing comfort (29). As a therapeutic strategy technique hypnosis is gentle, non-intrusive and child-centered (35).

Hypnosis and palliative care

When a child with a serious illness learns hypnosis, either as self-hypnosis or during psychotherapy, early during treatment it becomes part of the supportive therapeutic scaffold that the child leans on and builds upon to deal with life and death concerns (35-38). Routine self-hypnosis has the means to bolster the child's inner strength, or to conserve energy as his or her life force abates. In the imaginative engagement it provides a child with the experience of loved activities that can no longer be accessed but can still imbue meaning, sustain hope, ease despair, lessen pain and help to transport the child to places and experiences that diminish the threat of death, and ease their present experience (35). As part of a multimodal approach hypnosis integrates well with pharmacological, procedural, rehabilitative and psychological modalities to address distressing end of life symptoms, such as pain, nausea, vomiting, discomfort, anxiety, and existential distress. Detailed examples are illustrated in the cases below.

Adult data

Despite the paucity of controlled trials (39), there are data to support the use of hypnosis in terminally ill patients (40). Several reviews discuss the efficacy of hypnosis in adult palliative care (41-44) referencing clinical studies that show the efficacy of hypnosis in adult palliative care in symptom relief, such as anxiety, depression and sleep disturbance (44-47).

Pediatric data

Both in RCTs and case studies hypnosis and self-hypnosis has been shown to be efficacious in treating and preventing distressing symptoms such as chronic pain, headaches,

anxiety, chemotherapy-induced nausea, and acute pain during invasive medical procedures (48-63). Culbert and colleagues published a review and case examples of hypnosis in the treatment of pain children in different pediatric age groups (34). Published literature supports the notion that hypnosis appears to be a natural fit for seriously ill children receiving palliative care (36-38,64). The most commonly used integrative therapeutic interventions for children and adolescents in pediatric palliative or end-of-life care at the Palliative Care Program at the Children's Hospitals and Clinics of Minnesota (USA) and the free-standing children's hospice Canuck Place in Vancouver (Canada) were relaxation (64%), guided imagery (46%), energy medicine (39%), and hypnosis (32%) (65).

A classic pediatric example of hypnosis at end of life

In the first published article using hypnosis with a child (David) approaching death in 1976 Gardner (36) initially used hypnosis to treat his nausea and vomiting. Later, when David and his family realized that hypnosis might be used to enhance positive experiences, Gardner suggested that David have a pleasant hypnotic dream which he could repeat as often as he liked in order to experience safety and joy.

He dreamed he was an eagle who enjoyed flying from one safe and peaceful place to another; whenever anything disturbed him, he'd simply fly off to another, even safer and happier place.

David later started practicing self-hypnosis at home and triggered by his mother's suggestion, "David, just find your peaceful place", he was able to quickly move from a negative to more positive state of mind. Later Gardner used reverse hand-levitation in which she began by lifting the child's hand so that it was suspended in the air, and then gave hypnotic suggestions for the hand to lower to the bed, and for David to go into a peaceful focused state as the hand lowered. With this as the induction, she then invited David to engage with his familiar eagle dream so that he could achieve quietness and calm enjoyment. In considering their therapeutic goal she wrote:

For David and his family it became more possible to tolerate gradual physical deterioration and to avert the threat of psychological deterioration by learning to achieve a feeling of emotional ease and dignity. The sense of threat gradually gave way to a sense of challenge... enhancing his growing trust in himself (so that he could turn) his attention to solving problems rather than enduring them.

In their chapter "Hypnosis and Palliative Care" Kuttner and Friedrichsdorf described the previous case example by

Gardner, and in more detail, provided several case examples, describing the use of hypnosis in different pediatric age groups in PPC (35).

Use of hypnosis in children with serious illness

Self-hypnosis is the experience of turning inward, using one's internal resources and cultivating one's own imagination on purpose with the precise intention of accomplishing some definitive goal. The goal may be things as simple as helping one realize one already has the skill such as knowing that we become startled and then "un-startled" or we may need to teach ourselves to relax both physically and mentally/emotionally such as learning to calm one's rapid heartbeat or hyperventilation after a sudden startling event such as a near miss car-accident. Or, becoming aware that we already know self-hypnosis without knowing that we knew it, by things we already do, such as, for example, when we become embarrassed. A natural feeling that happens to everyone some times, being embarrassed is in many ways a good prototype for understanding the natural mind-body connection we all have and we all already know how to use, though we don't necessarily do it 'consciously'. Something happens (e.g., we stumble and accidentally dump the bowl of salsa on our nice white shirt), emotionally we get embarrassed (and maybe angry, frustrated too), physiologically we blush (vessels dilate, the face and sometimes other parts get red, we feel warm), then someone does something (we run away, we make some excuse or say something, someone helps us clean up), and we suddenly feel less or unembarrassed and, in turn, we stop blushing. Voila! This is a common example of mind-body interaction, much of it occurring "sub" or unconsciously. Learning and utilizing self-hypnosis involves first recognizing, then cultivating this natural skill, building it through rehearsal, practice as with any skill, toward a goal of increased comfort, reversal of a habit or creating an alternative pattern of responsiveness, resolution of discomfort, etc.

Misconceptions

Common misconceptions of pediatric hypnosis are discussed elsewhere (28-30), and include that hypnosis is not magic but sometimes the results of rather brief interventions. It can be quite dramatic as skills build rapidly in the face of high motivation and positive focus and positive expectations. Hypnosis belongs to the patient. The

clinician [and for young children, also the parent(s) or other significant others] is/are the coach(es), teachers, facilitators. Hypnosis is not sleep, though it can be a very effective intervention for the sleep onset insomnia encountered by many children with chronic illness, hospitalized, in hospice, and/or on multiple medications, which may affect sleep (28,29,35).

Phenomena of hypnosis

Phenomena of hypnosis (29) and how they may be cultivated in caring for children with chronic/serious illness and palliative care include time regression/progression; narrowed concentration, hypnoanalgesia, hypnoanesthesia, amnesia, dissociation, trance logic (allowing for two mutually exclusive events = being here and there at the same time in order to not pay attention to and/or not be bothered by what is happening here).

Indications and contraindications

Whenever there is an undesired symptom or problem hypnosis can be a very powerfully effective sole or adjunctive method for approaching/re-framing/resolving that symptom (28,29,35). Hypnosis contraindications are relative, not absolute. Hypnosis might be contraindicated only when there is truly no motivation for change or when the individual has a significant retardation or cognitive disability that they cannot comprehend or process verbal or non-verbal communication; or participate in communication meaningful to them. But, this does not preclude the offering of kind, sensitive, empowering suggestions gently and calmly to an individual—even if they are asleep or in a coma, and particularly so if one already has an established, positive therapeutic relationship with that child (29).

Finding hypnosis in the encounter

The key to effective utilization of hypnosis by children/families with chronic/terminal illness is, as with all utilization, application/training of hypnosis, the evolution of a positive, kind, thoughtful rapport with the patient(s). Though each clinician may do this differently with attention to personal style, the essential ingredient for clinicians is to "go with the child". This requires attention to all verbal and non-verbal communication from/with the child/family, honoring and respecting the child's choices (of imagery, activities, desired outcomes, imagined places to visit), and

being skilled, ready, and willing to allow the child to lead the clinician who can follow, pace, and lead the child toward the comfort and control that they desire and deserve.

Developing the skills to do this effectively with children and families requires not only understanding and desire, but training and practice (66). Pediatric Hypnosis training is available through the National Pediatric Hypnosis Training Institute (NPHTI) (67).

Finding the hypnosis in the encounter is an amplification of what Erickson described and emphasized as the utilization approach (68), reflecting his belief, practice, and teaching that the best hypnosis takes place in the interaction of the (skilled experienced) therapist and their patient. Much as an elite gardener might appropriately do to maximize the beauty and bounty of their flower and/or vegetable gardens, the clinician who is most successful is the one who assists and guides the child and family in the optimal cultivation of their imagination. This is accomplished best with an eye and ear toward the genesis of novel approaches to comfort, to alterations in patterns of responses and behaviors, and to modulation and modification of previously habituated or conditioned responses which have become ineffective, inappropriate, and no longer beneficial as they perhaps once were.

Over the years we have asked many of our young patients and their families to describe in what ways hypnosis has been effective for them. This experience of directly soliciting patient and family reflection on the nature and value of their hypnosis experience has been increasingly important to us in the ways we carefully attend to listening to and watching our patients as we work together, in the ways we formulate suggestions, and the ways we help patients teach us and other clinicians how to help other children and families (69).

Case presentation

In recent years I (Daniel P. Kohen) have had the opportunity to come to know and work with an increasing number of children, adolescents, and young adults with cystic fibrosis (CF). Each was referred with the specific request for hypnosis/hypnotherapy to help with one or more problems they were experiencing as part of their chronic and terminal illness and/or its treatment. Each benefited in definitive and, some might say, dramatic ways from learning the self-regulation strategy of self-hypnosis.

In thinking about presenting these young peoples' cases and the successful application of hypnosis to their particular

circumstances, it was apparent that they probably could tell their individual stories better than anyone else, and clearly and importantly "in their own voice".

Case 1 (K.)

K. was 13 years old at the time of these encounters and died at age of 23. She was 12 when her father called to request a meeting to discuss the possibility of self-hypnosis helping his daughter. He asked for help for him and his wife in rejuvenating the local CF parents' support group. Nine families (with children) came to a presentation provided about the potential value of hypnosis for CF for various symptoms and treatments. They viewed Leora Kuttner's videotape *"No Fears, No Tears"* (70) which describes applications of relaxation-mental imagery for children with cancer.

Six months later their daughter, 13-year-old K., came for her initial visit. She said that she was there for help particularly with the pain and anxiety caused by intravenous access. When asked what the five worst things of CF were, she said *"Doing all the things I have to do"* including (then) more than 30 pills per day, four bronchial drainage treatments ("they pound too hard"), *"I don't eat that much. I'm not hungry, I lose weight, then they nag and I have to gain it back or go back to hospital."* Her parents' goals were to: (I) help with K.'s self-esteem for K.; (II) help her eat more; (III) improve her "compliance" with medications, respiratory therapy, aerosols; (IV) help her headaches; (V) and (her father's stated goal for K.) *"to develop internal imagery of herself as healthy."* Parents also wanted to know what they could and should not do to be of help.

Imagery was introduced at the second visit by encouraging visualization of her favorite activity, i.e., horseback riding. During discussion of her imagery she moved in and out of a spontaneous hypnotic state with fixed gaze stare and report of active imagery. She spontaneously said she thought that ways that hypnotic imagery might be able to help her included: (I) *"Taking medication without thinking about it. Hard part is the taste"*; (II) taking antacids even with the chocolate in this high caloric drink she said she stalls around a lot, takes 10 min to drink. Discussion followed about time distortion in daily life, like how we say "time flies when you're having fun" or how it seems to move very slowly when you're nervous or anxious to get something finished; (III) *"I have to gain weight"* even though she says her appetite is normal and good. She seemed happy to learn that there

is an “appetate” in brain; and developed a picture/image of how it might look so she could adjust it in her mind’s imagination; (IV) pain control switches for IV/venipuncture comfort. Following the “waking suggestion” presentation of these ideas, K. was invited to “*just think about the stuff we talked about and next time we’ll learn how to do self-hypnosis.*” At the next visit she was taught a simple self-hypnosis technique with eye closure, and appeal to curiosity with the teaching of peripheral temperature biofeedback as a metaphor for control. During this first formal hypnotic experience her peripheral temperature increased by 9.8 °C. Her multisensory open ended imagery included reporting riding her horse, Sally, in a meadow, or somewhere else. Progressive relaxation was taught and used for deepening and specific therapeutic suggestions included visualizing the taste switch, turning it way up and imagining a candy bar or other snack while out riding horse. She was invited to notice the changes that occur (happen!) when focus her mind, e.g., such as spontaneous slowing of respiratory rate (RR). She was encouraged to find the appetite center, adjust it to be safe and comfortable, just the right amount to gain the right amount of weight and for normal growth. Suggestions were given that the pills and the antacid could taste like candy, and that the nebulizer aerosol could also taste like candy or whatever else she wanted.

She was taught self-hypnosis during this first trance, and the session was audiotaped, with music in the background. Metaphoric story-telling concluded the trance with emphasis on younger children who had taken a trip through their body, visited the computer we call the brain, adjusted whatever needed adjusting.

At the next visit practice of self-hypnosis included learning how to do and use ideomotor responses to “*get automatic signals from your brain to your body to help you when you practice by yourself and you’ll know you’re doing it right and well...*”. Imagery suggestions were offered that she could “*give directions and instructions to your white blood cells to eat the bacteria and the viruses they needed to eat. Or to imagine a Ms. Pac-Man (popular video game at the time) or a vacuum cleaner going through your breathing tubes and gobbling up all of the mucus.*”

By the end of the 5th visit (over 3 months) K.’s parents reported dramatic improvement with weight gain, eating better, taking antacid and medications as directed, and surprising her CF pulmonologist at a recent visit with how well she was doing! (In the same period the parents were also counseled to back away, and to decrease nagging.) Follow-up visits were decreased to monthly.

At a visit a month later K. was asked how she’d explain (her) self-hypnosis to another kid and she said “*Well, I’d tell them it hurts to do the vest, but if you do the imagery it will help you... I just relax and imagine stuff.*”

Over time self-hypnosis and storytelling were used for various interim anxiety producing events, such as being able to get back up on her horse after having been thrown off (hypnotic suggestions for amnesia “*that was then and this is now, remember to forget to remember to forget...*”); coping with anticipatory anxiety of surgery for ingrown toenail (revivification of dental anesthesia used hypnotically); coping with the acute grief and personal fear when a friend with CF died, and two other friends were “*back in hospital from not taking good care of themselves...*”; dealing with broken wrist (no pain!)

After not coming in for nine months, K. arrived for a follow-up visit. At the time in 9th grade she reported some typical adolescent adjustment issues, such as being with a boyfriend much older, hiding some pills, skipping some meds on purpose. She agreed she might be “a little” depressed. She agreed to meet every 3 months but not more often. She managed to re-start taking her medications, and said that she uses self-hypnosis “*when I need it, like IV’s or major headaches.*”

She was intrigued with the doctor’s invitation to write about her use of self-hypnosis for her CF and said she’d write about (I) headaches; (II) forgetting ideas (amnesia); (III) “*by telling myself to have it go away, I can control it like CF...*” (IV) Appetite; (V) for taking all those pills “*I used to gag and tell myself to take them no matter what, just to get better.*” (VI) “*Switches, by turning off the switches for something like the supplements I have to take, I turn off the taste...*”

Letter from the patient

I was introduced to imaging (sic) 3 years ago when I was very sick, loosing (sic) weight, not eating, taking pills, and generally giving up on living. I was taught different methods of imaging to help my appetite, taking pills and for controlling CF and not have CF control me. I also use imaging for other aspects of my life and disease.

Because of my CF my body does not use all the food I eat. My body also uses 2,500 calories while I am sleeping. I need to eat between 5,000 to 6,000 calories a day. At first I thought this would be great I could eat all I want. However, after a while I got tired of always having to eat and always taking pills. My imaging helps me with this problem. I tell myself I must get a bigger appetite. I tell my stomach to feel empty and hungry for I have to eat no matter what. I also

visually picture the food as being something else and tasting like something totally different than what it is.

When I first left the hospital I had to have four IV therapies every day. Shortly after that I started gamma globulin IV therapy every other week. Sometimes I had to be poked 3–4 times before the nurse could find a vein. When she finally got it started it would take 4–5 h for the solution to drip slowly into my veins. Half way through each session my vein and arm would start hurting quite a lot. Now with imaging almost all the time my nurse can get a vein on one try. This is how I do it. Just before the nurse gets ready to poke me I have to have perfect silence. During the next 2 min I picture my veins and tell them to fill up just like a swimming pool. My veins become the pool and the water is actually my blood that must fill up the veins so that they will stand out and stay up. As the nurse starts to insert the needle she tells me she is going to start. Then I tell myself that there is no such thing as pain and feel nothing as the needle goes in.

I also use imaging for pain. This pain comes from my IV therapy, or when I have headaches, or pain from my ankle, nasal, and toe surgeries. The way I control this pain and make it go away for good without taking pain medication is my mentally seeing a large pool filled with warm and gentle water. This pool has 10–20 steps into it. What I see is myself going slowly down the steps. With each step the pain gets less, until by the time I get to the bottom and enter into the gentle, warm water my pain is gone and I feel good. An example of this is when I had extensive toe surgery for a really bad ingrown toe nail. First my mom and dad went into the or room with me and I had my mother talk to me about riding a horse to a large swimming hole surround (sic) by flowers. I get off the horse and swing my toe in the warm and gentle water. This way I do not feel the needles going into my big toe. Then all the way through the surgery, since I am awake I keep my eyes closed and picture the same scene and smell the flowers. After it is over I take the horse back to the barn and get off and wake up. After this surgery the doctor wanted to give me pain medication, for he had to do extensive cutting. Instead I used the pool and the steps and instead of pills I went to the Red Lobster 1 and 1/2 hours after surgery for a huge meal. The next day I walked all over the University of Minnesota Hospital for testing for my CF.

Because I have to take about 200–300 pills a day, I use imaging to not taste the pills. I also tell myself that by taking them I will be healthy some day and not have to take pills ever again. I also see them not as pills, but as Jolly Ranchers or some other candy that I love to eat. I also tell

the pills and myself that I have to take them to get better and keep my weight up, for without the pills my body does not digest 80% of my food.

Another part of the imaging that I use is switches. This is a light switch with an on-and-off button or a round switch that goes from high to low. I use the light switch for controlling my taste buds. I turn off my taste buds when I have to take my awful tasting supplements and for eating foods I do not like or I am tired of. I use the round switch to turn off my pain slowly so that I see and feel it leaving.

The last way I use mental imaging is for controlling my CF and getting sick. When I get sick I tell my body to take control of my bacteria such as *Pseudomonas cepacia* and to dispose of it out of my body. I also tell myself and my body when I start to get sick that CF will not control me, I will control it. I do not want to be sick, I want to be normal and go to school and enjoy my life to the fullest. Mental imaging has changed me in many ways. It has allowed me to lead this more normal life and to control the things I have to endure.

Case 2 (Z.)

Z. was a 16-year-old young woman when she came to learn about hypnosis. With her underlying CF she had relatively minor lung disease and none at all until age 11 years old. Her mother, a clinical psychologist, attended a clinical hypnosis workshop where one of the authors was speaking. After the presentation she approached the presenter and asked if hypnosis could help her daughter whom she described as having “*mild CF with tremendous anxiety about needles.*” Z.’s mother was quite confident and enthusiastic after her first workshop that the techniques she had just learned for herself and for her own clients would be useful for her daughter; and she was equally confident (appropriately and admirably so!) that she was not the right one to teach or help her daughter learn and use hypnosis.

At their first visit the strength and positive nature of the maternal-adolescent bond was evident in this bright, engaging young woman who spoke openly about her excitement about the potential for hypnosis to help her. Her clear and major focus was on her anxiety about needles. Her focus was especially upon the forthcoming surgery for removal of nasal polyps and her associated fear of needles, intravenous access (IV’s), anesthesia, etc. Almost as an afterthought, she wondered aloud if she might learn “*how to get rid of the polyps with hypnosis?*”

Reflecting and mirroring her own enthusiasm (finding

hypnosis in the encounter) she was assured her that the doctor was very confident that she could learn easily to use self-hypnosis and to modify her body's responses to her disease and to the associated stresses thereof. Z's mother was encouraged to take a minimal involvement role at Z's discretion. Mother was calm, content, confident.

As in her own words below, Z. was very successful in applying self-hypnosis.

At her first visit, she said *"I heard that hypnosis might help with my health. I think it's like someone talks to you and you take in information while you are relaxed and you feel more relaxed and then you help yourself."* She said that she thought this visit was *"to maybe help my health better..."*. In a series of discussions in the first visit, indirect hypnotic-like suggestions and seed-planting were provided for future hypnotic visits, for example, she explained that *"I just don't like IV needles, give me the creeps... from when I was a baby, I was failing to thrive and it's like kind of hard on you... first time from my own memory I freaked out..."*. With no particular discussion about it, her positive expectancy and enthusiasm triggered a memory for the doctor of the renowned Dr. Milton Erickson saying *"go with the patient"*, and so the doctor matter-of-factly invited her to *"Think back to the first time you had an IV..."* and she went into a hypnotic trance. She was invited to remember that she was younger then, didn't know as much as she knows now. In present tense language and a younger voice, she said *"I'm lonely, I want to go home..."* reflecting the revived preschooler in the hospital.

Out of trance she was invited to measure the feeling of nervousness on a self-monitoring scale of 0–10. By the end of the first visit she agreed that at the next visit she wanted to formally start *"learning and doing hypnosis"* at the next visit. She said that besides being with her friends she enjoyed being with her animals, noting, *"my animals calm me down"*.

At her second visit a week later she viewed a video of other teenagers learning and talking about hypnosis. She and her mother reported that in the interim a decision had been made to have her nasal polyps out in 4 weeks. Mother asked if hypnosis could be helpful in making the polyps shrink or disappear by then. The doctor indicated that he fully believed that was possible (but didn't know how much of it could happen by the time of the scheduled surgery).

The first formal hypnosis session followed, and was audiotaped for her use at home. With a solid rapport begun at the initial visit, Z. responded promptly to a simple invitation to *"Well, to begin, just go ahead and close your*

eyes... that's right" Within seconds eyelid flutter, rapid eye movements under closed lids, and slowing of her RR were "fed back" to her as trance ratification, and intensification/deepening suggestions. Multisensory imagery and progressive relaxation furthered the intensification. In trance she reported active imagery of being by a lake or with her animals, and reported noticing tingling in her hands. This dialogue guided the clinician to develop the obvious suggestions for numbness, glove anesthesia, and the ability to be in charge of memory, remembering this, letting her hand (and arm) remember the numbness while forgetting prior IV experiences *"which were way back then anyway; and to be surprised how easy future IV's could be..."*.

As the trance progressed storytelling suggestions were offered, telling her *"you know, I knew a kid once who told me that she enjoyed pretending taking a trip around her body... that she was so tiny, and she went for a trip in a boat or jet ski in her bloodstream, or on a motorcycle on her bones and nerves..."*.

Z. reported that she saw her polyps and sinuses, and that they *"looked like clouds that were kind of yellowish white."* In response she was invited to let it be a clear day, to watch and enjoy the sunlight, and later she said *"it's clearing up now"*.

Another story was told about a (purposefully younger) girl I used to know who took a trip through her body to lungs, used a "vacuum cleaner" to clear mucus out of her lungs for her asthma, and to tell her breathing muscles to relax. A related suggestion offered the idea that Ms. Pacman could be imagined making her way through the breathing tubes, gobbling up the mucus (see case 1).

Integral to this first experience she was taught how to do self-hypnosis and offered many ego-strengthening suggestions for how wonderfully well she had done in learning. During the de-briefing after she re-alerted she offered a remarkably vivid description, *"It was real green grass, a very nice path... and in my mind I had my dog eat the polyps..."* and (when testing for hypnoanesthesia) *"I couldn't find my arm for a minute there..."*. She agreed to practice self-hypnosis 10–15 min, twice a day.

The third visit was 2 weeks later. She was asked to explain to a visiting Pediatric Resident what her reasons were for these visits. She said *"I'm here to get rid of my polyps that used to be there and to use hypnosis to not be afraid of IV's anymore... I do hypnosis while I'm sleeping. I start with a tape, then I fall asleep, and I also do it 2 times a day myself in the daytime."* Asked to teach the resident and the treating physician as though they knew nothing about hypnosis, she readily did so:

“First you go to an area where you’re comfortable, then sit down and then shut your eyes, and go where you wanna (sic) be in your imagination—choices... sit wherever you like and relax, slowly but surely, your whole body and then put a message in the corner of your mind, whatever you want to give yourself, in my mind my dog eats my polyps...”

Specific suggestions were added to enjoy breathing, to *‘breathe in comfort and breathe out tension; pay attention to the tension that goes away...’* and *‘to get all the air you need when you need it...’* Switches imagery was taught to hypnotically modulate perception of sensations such as pain.

After practice, she reported that *“I went to three spots, and there were three different animals. There was Spanky my dog, there was also a cheetah, a Bengal tiger, and a scarlet macaw all gobbling up my polyps.”*

Z. returned for her 4th visit and 3rd hypnosis session 5 days before the scheduled surgery. She reported that her intuition told her that the “polyps are gone”. Though she and her mother requested a follow-up CT scan before surgery, their physician and surgeon declined, noting that insurance would not pay for it. At this 4th session she was taught cues for quick RMI with posthypnotic suggestion signals, switches were rehearsed, and the two-screen technique was introduced, with one screen showing a previous memory and another with a “future memory”, and the invitation to *“create the future memory of yourself getting the IV, smiling, proud, happy...”*. She was invited to keep the polyps in check, monitor their growth, provide the switches. On this day she was asked if she would be willing to write down how hypnosis helps her and she agreed.

A week later, after the surgery, Z.’s mother left a phone message that at surgery the ENT surgeon found “no polyps for the first time ever” (though they had been there on X-ray before treatment with hypnosis) and that Z. had never had as healthy a month as she’d had since learning self-hypnosis.

Two weeks after the surgery Z. explained to her doctor that pre-operatively she had run 12 laps with her dog, never having done that before. The ENT doctor reported that what had previously been polyps large enough that *“they had already begun to hang down toward out of the nose”* were now *“hardly only little buds”* and he had *“observed marked regression for reasons not very clear to him...”*.

In a follow-up visit several months later Z. was clinically quite well! She reported *“I sit down or lay down, I tell my body to relax, I go through each part of my body. For me I use jungle animals or my dogs to eat my polyps or my mucus, I tell myself to...”*; *“I’m very relaxed, I have more energy”*. Her doctor *“thought I was crazy”*, some of my friends *“think I’m nuts...”*.

While she had recently been in the hospital for 7 days with pneumonia *“it was the shortest one I have ever had... I told my veins to be better; IV lasted for 6 days! I was using hypnosis for most of it (hospitalization)”*.

In Z.’s own words

“I’m here to get rid of my polyps that used to be there and to use hypnosis to not be afraid of IV’s anymore... I do hypnosis while I’m sleeping. I start with a tape, then I fall asleep, and I also do it two times a day myself in the daytime.” She said *“First you go to an area where you’re comfortable, then sit down and then shut your eyes, and go where you wanna be in your imagination—(choices)... sit wherever you like and relax slowly but surely your whole body and then put a message in the corner of your mind, whatever you want to give yourself, in my mind my dog eats my polyps...”*.

She explained that her CF was mainly in her pancreas, but more recently in her lungs, got pneumonia... and *“Since hypnosis I really don’t get any mucus; I told myself I don’t want to get any...”*.

Letter from Z.

Dear Dr. Kohen

I just wanted to thank you so much for helping me learn how to hypnotize myself! It has helped me in so many ways!

As you’ve already heard, the polyps in my sinuses were almost totally gone! There were just a few buds. Unfortunately, I still had the surgery, due to the X-ray (Waters’ view) showed that my sinuses were totally occluded. It wasn’t until the surgeon performed the surgery that it was found otherwise. What was really shown on the X-ray was scar tissue from previous surgeries that had been done 5–6 years ago.

In the last few hypnosis sessions I gave myself before my surgery were unreal. As I have having my dog Spanky, a blue and gold macaw, and a Bengal (sic) tiger eat my polyps, a rush of brown stuff like a river came rushing threw (sic) my sinuses! This is I think when my polyps were pretty much abolished! I then was doing my hypnosis with the same animals as before, and all of a sudden the entire jungle was in my sinuses eating the polyps. Then all the jungle animals rushed down into my lungs and started eating. And rush of brown came again threw (sic) my sinuses! I was in shock along with my mom!

My attitude on life has changed drastically! I now know that I have to ability to make things I need in my life happen! Hypnosis is going to be a part of my life forever. It’s also a great way for me to let go of unneeded stress in my daily life!

Thank you for showing me the way. Sincerely...

Case 3 (S.)

Almost 7 months before coming for her first visit, 6-year-old S. was discussed with the treating clinician by several colleagues. Referred by several pediatric gastroenterologists, S. was first described as *“a child with underlying CF, she is someone who needs to eat, but either can’t or doesn’t”*, and in whom sophisticated medical evaluations had failed to reveal a reason. A 6-year-old with more extreme (and unusual) GI symptoms than most with CF ever develop, she was thought of as a diagnostic enigma. The cause of recurrent massive gastrointestinal bleeding, nausea, abdominal pain, and especially back pain in various combinations had yet to be definitively identified. Motility studies showed no difficulties in swallowing. Consultation at two major Midwest pediatric medical centers revealed no new explanations. An effort was made to allow and expect her to eat by decreasing tube enteral feedings. She showed a remarkable appetite, a more than adequate caloric intake of >2,000 calories/24 h but subsequently developed massive gastrointestinal bleeding; again without explanation. Surgical, radiologic, pulmonologic, and gastroenterologic diagnostic and therapeutic approaches revealed no explanations. Night feedings through a gastrostomy continued. Efforts by her GI physicians turned to focus upon *“normalizing her life”* so she could go to school without gastrostomy feeds at school, and the hope that she wouldn’t have to have night drip feeds.

In turn her mother was portrayed as *“controlling, over-involved, manipulative and over-protective—and a nurse besides”*. A highly skilled adult intensive care nurse, the mother was both heavily involved and protective, especially with the ongoing uncertainty, the unpredictable *“misadventures”*, and vulnerability of her daughter.

Mother agreed to meet after first agreeing with the GI specialist that perhaps S.’s eating problems could be more of a habituation to not eating. Shy initially, S. eventually said *“I’m here to help me learn to eat... cause I am not hungry, I eat at night (tube feeds)”*. She was definitive about what (snack foods) she eats and doesn’t eat... She agreed that we eat *“to stay alive”* and told the new doctor that *“I have CF, it’s a disease I am born with. They are thinking of a cure for it and we are going to go on a walkathon... I have a pump at night too... it gives me fluids at night because I don’t drink enough... it goes into a button into my stomach and my tummy and there is a tube and it goes to a pump and there is a formula that goes into the fluid to keep me healthy”*.

At the end of the first visit S.’s mother had very low

expectations, some disdain and a negative mindset about *“behavior”*, noting clearly that S. and her pain, poor weight gain were not behavioral problems. They had a previous very negative experience when S. was 1 year old. She was *“failing to thrive”* and a therapist insisted upon a rigorous procedure of behavioral modification. Mother also described the misadventure of a fundoplication procedure (Nissen) in infancy which *“ripped open”* and noted dramatically that she thought S.’s eating problems dated from that time, age 6 months.

Mother’s helplessness was reflected in, *“I would do anything to help her eat, I don’t have a clue why she does not eat more... She can eat... ate 2,000 calories last year... GI bleed... not manipulative behavior, my older one is manipulative I know that...”*. She agreed to go slowly, and to discuss this from the perspective of being a habituated behavior.

At the second visit she reported that S. was just discharged from a 1-day hospitalization with severe back pain. S. was very positive, and mother was happy that S. had said she was eager to continue to come to the *‘new doctor’*.

The discussion focused on supper, and talked very comfortably about food. A history of prior hypoglycemic coma was revealed.

It seemed clear that S. was not *“orally defensive”* or *“food aversive”*. The initial impression was that her situation was one of predictable and understandable *“high anxiety”* about turning down tube feedings to drive appetite and risking weight loss and pulmonary complications.

Discussions with her mother focused upon *“choices within limits”*, a de-sensitization approach but also revealed when a chart of food intake was suggested, that the mother (not the child) was chart aversive! Modeling was done with mother to demonstrate ways to involve S. in a positive expectancy *“what do you think we can write down about what you will start eating for breakfast, lunch, and dinner...let’s start with breakfast... catch her readiness...”*.

Beyond the eating difficulty, mother was faced with the CF specialist being very definitive that S. *“had to”* maintain a critical weight to maximize fending off the respiratory infections, which could debilitate and kill her.

During inpatient visits the new doctor’s focus was, as Erickson insisted, to *“go with the child”* and in her case, therefore, to *“go with the mother”* since they were so interdependent, in some ways not very much different than one might expect or hope for a child of 6 without a chronic illness, and certainly not much different than what one might expect in any parent-child pair where chronic illness, fear, and uncertainty drive people’s lives.

Focus continued on working with and through S.'s mother, i.e., on teaching the mother principles underlying self-regulation (such as hypnosis) in the context of her child's level of development, personality, strengths (intellect) and perceived weaknesses (whiney, "stuck" in negative habituated responses). The work included emphasizing the importance of language (for example, in a humor-based context mother was relentlessly reminded that "we" are not nauseated, but "S." was nauseated; and not "she is nauseated all the time" but, rather, that she "has been nauseated a lot of the time"). Such repeated re-framing, slowly but methodically eased S.'s mother into a posture of being willing and able to help guide S. in the direction of self-management. At a care conference emphasis was placed upon the concept of pain as a perception for which self-regulation was do-able, in order to facilitate staff believing that S.'s hurt was of course real, and in turn mother believing that the staff were in fact on her side.

All were encouraged to refer to S.'s pain as her "discomfort" and to not use the word "pain" at all. Emphasis continued on the natural imaginative abilities of children (and adults) and in the process hypnosis was demystified, and focus was on the elements of "relaxation and mental imagery" or visualization. Mother was given specific instructions how to be S.'s coach, and things to say to her, for example, when she was experiencing acute discomfort.

Mother began to understand and "try on" new language, such as "I wonder how we can get it down to a '9'". She was taught how to provide re-framing, imagery, relaxation, use of imagined switches to modulate discomfort. In this fashion mother was helped to focus on the power and value of specific language.

As S.'s mother was taught and coached, the doctor had to often "fend off" many of the other staff who were expecting and hoping that S. would be "hypnotized" and therefore somehow magically have her problems be solved.

Discussion with S. aimed to encourage and amplify her natural imaginative activities, finding out what worked for her; using liberal uses of humor, waiting for signals of comfort from her to know when it would be best to "jump in" and offer some "techniques of comfort". She loved to go shopping for toys and could be best described as "highly indulged". So, imagery of her favorite toy store became useful. Each night, her mother guided S. through walking down the aisles of the toy store, noticing everything on the shelves, buying whatever she wanted, etc. Mother taught and reported "I told her just go there and tell me about it" S. did and the distraction and imagery was the end of

complaint of back pain. Mother was proud.

Later, while she was in the hospital imagery was added of being in Africa on a safari, coolish warm air particularly to obviate the hot feeling associated with nausea (and vomiting). Imagery of a trip to North Carolina 1.5 years ago and driving trips around Wisconsin were added.

S. was taught about switches; and then taught the imagery of the magic glove to create glove anesthesia and, from that, to direct numbness/comfort to some other part of the body as needed. This was then linked to the idea and feeling of her back having a memory of its own, of knowing the feelings of her back being rubbed when not being rubbed "so you can have a back rub in your mind whenever you need it...". An audiotape was prepared and focused on the use of multisensory imagery, progress, relaxation, imagery of being somewhere else, switches to turn off discomfort, references to back pain or nausea, cool breezes, zebras, boat ride, car ride, and wind in face.

Soon thereafter her mother reported that "she uses her stuff (RMI) in small ways, like images herself swimming with dolphins, and her episodes (of pain) are just not as big or as big a deal as before." Nausea occurred mostly in the mornings after drugs. And her back pain had disappeared.

While S. was and is a so-called good hypnotic subject like all kids really are, success was predicated on not only working with her, but more importantly in engaging her mother in an understanding of and provider of the role as guide and coach, while the treating clinician provided the coach role for the mother and reinforcing role for S.

Discussion

In summary, the therapeutic suggestions for CF in these patients, and their parents (71), were for (I) pain control, including distraction, dissociation, switches to turn down or turn off pain, and amnesia for previous (painful) experiences; (II) anxiety control via distraction or dissociation, relaxation, focused breathing, the Jettison technique (i.e., throwing away or 'jettisoning' bad feelings), and their varied personal imagery; (III) taste control through the switches technique and negative and positive hallucinations; (IV) nausea control through use of imagery, distraction, dissociation; and (V) general disease perception and modification with the use of imagery and future projection.

Rather than over-state or over-value the role of hypnotherapy, the intention reflected in these cases is to recognize the breadth of the spectrum of possible actions and reactions in the total experience of a child with a life-

limiting disease, in these cases with CF, who use their personal hypnosis skill(s) which they were able to realize that they had and were able to cultivate and develop to their advantage. Thus, in the context of perceiving hypnosis as one resource amongst many, each affects the others in the broadest context of experience. While for each of these patients with CF hypnosis played a particular and unique role in their lives, some generalizations can be made from their experience, not only to others with CF, but also to others with chronic/terminal illness. The application of hypnotic strategies to help modulate the uncertainty and associated anxiety, which are hallmarks of chronic illness is perhaps its most valuable asset. The ability to teach young people to utilize their hypnosis skills to reduce, manage, or eliminate the fear of loss of control was evident in each youth described; from controlling the taste of the 100's of pills or other medications, to controlling discomfort associated with various procedures. While curative treatments might be on the horizon for CF, the knowledge that anxiety can be managed with the aid of hypnotic strategies is a great comfort to those already in the end-stages of the disease, and suffering the anxiety with dyspnea, hypoxia, and associated sleep deprivation. The ability to take a measure of control of appetite, to exercise control of weight and thereby affect the course of pulmonary problems provides not only comfort but potentially adds life to this still life-threatening disease.

Pain control in all of its forms and through the application of various hypnotic phenomena allow help to provide the relief of suffering desperately desired by those whose disease and its treatments consume many if not most waking hours of each day. Whether switches imagery, hypnoanesthesia, distraction, or negative hallucinations, their application to headaches, abdominal pain, surgical procedures, or routine blood tests and intravenous therapies have proven to be symbols of the sense of empowerment and comfort young people with CF can achieve as they learn and practice the self-regulation strategies we know as hypnosis.

Conclusions

More than 20 million children would benefit from PPC annually worldwide, with more than 8 million children in need of specialized PPC services (1). Even in resource-rich countries of the European Union and North America the majority of children dying from serious advanced illnesses are still suffering from unrelieved, distressing symptoms such as

pain, dyspnea, nausea, vomiting, and anxiety during their end-of-life period. Advanced effective treatment and prevention of those symptoms requires employing “multi-modal” therapies, commonly including pharmacology, rehabilitation, procedural intervention, psychology, and integrative modalities. This article describes the current practice of effectively integrating hypnosis into advanced pain and symptom management of children with serious illness. Hypnosis for pediatric patients experiencing a life-limiting disease not only provides an integral part of advanced symptom management, but also supports children dealing with loss and anticipatory loss, sustains and enhances hope and helps children and adolescents live fully, until death. Clinicians taking care of seriously ill children may consider adding hypnosis as one tool into their toolbox for appropriate patients, when providing PPC.

Additional resources

- (I) Pediatric Hypnosis training is available through the National Pediatric Hypnosis Training Institute (NPHTI). Information is available at: www.nphti.org;
- (II) *Making Every Moment Count* [2003]—38 min documentary on pediatric palliative care that examines the experiences of five children (birth–19 years) who are facing death. Available through National Film of Canada: www.nfb.ca (1-800-267-7710), or Fanlight Productions, Boston Mass (1-800-937-4113);
- (III) Little Stars is tells the surprisingly life-affirming stories of young people around the world living with life-limiting illnesses. Information is available at: <http://www.littlestars.tv>;
- (IV) EPEC-Pediatrics, funded 2010–2017 by the National Institutes of Health/National Cancer Institute with a US\$ 1.6 million grant (NIH grant number: 1 R25 CA151000-01), represents the most comprehensive pediatric palliative care curriculum. Information is available at: <http://bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html>. (Contact: EPEC.Pediatrics@childrensMN.org).

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Footnote

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Informed Consent: We failed to obtain the informed consent as the patients have either died or moved away from the region.

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