



DMT WITH INFANTS, CHILDREN, TEENS, AND FAMILIES

DANCE/MOVEMENT THERAPY FOR INFANTS AND YOUNG CHILDREN WITH MEDICAL ILLNESS

Treating Somatic and Psychic Distress

Suzi Tortora and Miri Keren



“Integrating their shared experiences, the authors, Miri Keren as an infant psychiatrist and Suzi Tortora as a dance/movement therapist, have put together an extraordinarily valuable text focused on the impact of serious medical illnesses on the development of very young children. Particularly important is the emphasis throughout the book on how very young children’s development, both healthy and/or dysfunctional, is fundamentally shaped by nonverbally based physiological, sensory-motor, and affective interchanges between infants and their caregivers, interchanges that are internalized and become deeply “embodied” in the child’s psyche. Building on this fundamental aspect of early development, the authors provide detailed descriptions of the mechanisms underlying young children’s vulnerability to medical procedures and the potential immediate and long-term effects, the ways in which parents and medical personnel can help to reduce these potential traumatic effects, and rich descriptions of clinically effective nonverbal dance-movement techniques involving both child and caregiver. This richness of material will apply not only in work with seriously ill young children but with any young child who has experienced trauma. A special treat for every reader, not just those who work with the medically ill but any caregiver of very young children, will be the tables and appendices that describe the huge range of nonverbally based observations that caregivers can utilize to read young children’s physical, mental, and emotional states.”

Theodore Gaensbauer, M.D., *Clinical Professor,
Child and Adolescent Psychiatry, University of
Colorado Health Sciences Center, Aurora, Colorado*

“Drs. Tortora and Keren offer a very accessible volume here, contributing to the maturation of medical dance/movement therapy (DMT) with specialized applications for this population. The authors’ vivid descriptions of clinical sessions are a fabulous introduction to DMT for the reader unfamiliar with this mind–body integrated creative arts therapy discipline. Professional clinicians and graduate students will get close-up insights to how seasoned, intuitive, and expert therapists go about this sensitive, essential work on a moment-to-moment basis. Educators will appreciate how each well-referenced chapter can stand on its own. Theoretically rooted in development, trauma, embodiment, intersubjectivity, and regulation theories and research, integrated with practical models for pediatrics and DMT, the book exemplifies the interdisciplinarity that potentiates all medical DMT and indeed, all good health care delivery.”

Sherry Goodill, Ph.D., *BC-DMT, NCC, LPC,
Clinical Professor, Department of Creative Arts Therapies,
College of Nursing and Health Professions,
Drexel University, Philadelphia*

“To begin to understand how significant illness affects infants and children is quite daunting – this work by Dr. Tortora and Dr. Keren is excellent in exploring the intersection of experience and development with the added important insight of how dance/movement therapy can be used to intervene in these situations. I’m glad to know this work now exists, strengthening our understanding of the power of dance and movement.”

Nirupa Raghunathan, M.D., *Director, Pediatric Integrative Medicine, Integrative Medicine Service, Department of Medicine, Memorial Sloan Kettering Center, New York*

Dance/Movement Therapy for Infants and Young Children with Medical Illness

This book presents dance/movement therapy as a window into the emotional and internal experience of a baby with a medical illness, within the context of treating the whole family system and using the DC: 0–5™ as the basis for formulating the clinical situation.

This book fills a gap in the literature, bringing a variety of fields together including infant mental health, infant and child psychiatry, nonverbal movement analysis, and the creative arts therapies. Grounded in a biopsychosocial perspective, dance/movement therapy is introduced as the main treatment modality, using nonverbal expression as a means of communication, and dance and music activities as intervention tools, to support the child and family. Vignettes are presented throughout the book both during and years after the medical experience, taking into consideration the subtle and more obvious effects of illness on the child's later emotional, social, and behavioral development. They illustrate the expertise of the authors as infant mental health professionals, drawing upon their work in hospitals and private practices, and highlight their unique perspectives and years of collaboration.

This exciting new book is essential reading for clinicians and mental health professionals working with infants and their families.

Suzi Tortora, Ed.D., BC-DMT, LCAT, a board-certified dance/movement therapist and specialist in the field of infant mental health and development, has a private dance/movement psychotherapy practice in New York City and Cold Spring, New York. She is the International Medical Creative Arts Spokesperson for the Andréa Rizzo Foundation and senior dance/movement therapist at Integrative Medicine Service, Memorial Sloan Kettering Cancer Center, NYC.

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DMT with Infants, Children, Teens, and Families

Series Editor: Suzi Tortora, Ed.D, BC-DMT, LCAT, a board-certified dance/movement therapist and specialist in the field of infancy mental health and development, has a private dance/movement psychotherapy practice in New York City and Cold Spring, New York.

DMT with Infants, Children, Teens, and Families provides a detailed overview of all the applications of dance/movement therapy nationally and internationally, from its ancient roots in tribal healing rituals to its current uses in medical settings, schools, and private practice to support families and their children, including those with medical illness, generalized anxiety disorders, sensory processing disorders, autism spectrum disorders, eating disorders, trauma, multigenerational trauma, identity issues, and work with immigrants, refugees, people of color, and underserved populations.

The international authors contributing chapters to this series include early innovators, established leaders and young professionals bringing new perspectives to working with children and families. These diverse voices build a discussion about the use of dance to heal children using a multicultural lens that is sensitive and inclusive, with full awareness of the underlying influences power, privilege, and oppression have on servicing these populations. Each book includes theoretical/methodological and empirical chapters with many vignettes illustrating DMT in action, in addition to discussing the most prominent innovators in the field both historically and currently.

Dance/Movement Therapy for Infants and Young Children with Medical Illness

Treating Somatic and Psychic Distress

Suzi Tortora and Miri Keren

For more information about this series, please visit www.roughledge.com/DMT-with-Infants-Children-Teens-and-Families/book-series/DMTWICTAF

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In memory of Andréa Rizzo, whose spirit graces every one of these pages, and in dedication to Susan Rizzo Vincent, Andréa's mom, who took Dréa's vision and made it a reality.



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Foreword

For infants and very young children experiencing grave and life-threatening illnesses, the world can be inhabited by pain, distress, uncertainty, and sometimes the terror of aloneness, especially when parents and others may feel unable to connect and engage with the child. This unique book, authored by Dr. Miri Keren and Dr. Suzi Tortora, both of whom I am privileged to know through our mutual connections with the World Association for Infant Mental Health, provides a vibrant and comprehensive rationale, pathway, and methodology for reaching out to enter the world of the distressed infant or young child, providing real therapeutic opportunities.

During my long career as an infant psychiatrist in a pediatric hospital setting, I have seen many young children experience considerable pain and distress due to illness and necessary but sometimes severe medical trauma. Keren and Tortora are among the few clinicians who have researched and informed us about the impacts of severe and chronic illness upon infants and preschoolers, especially those who endure long and frequent hospitalizations with concomitant medical trauma. For many years, I have been inspired by the depth of Keren and Tortora's understanding of the medically traumatized infant, and by their creative approaches to psychotherapy to alleviate infant and parent distress.

Major advances in the surgical, medical, and nursing care of young children with life-threatening disorders such as childhood cancers, congenital cardiac anomalies, and gastrointestinal disorders, including short gut syndrome, mean that children who may not have survived in an earlier era can now survive through childhood. But they often require intensive, prolonged, and frequently intrusive and painful treatments. As a result, practitioners in the field of child mental health have had to develop and adapt infant and family interventions to support these patients and their carers.

Infants comprise more than 10 percent of children who present with pediatric cancer. Researchers in related fields have stressed the importance of approaching the care of children experiencing cancer through the lens

of post-traumatic stress, which affects the child and the family (Kazak & Baxt, 2007). Without attuned therapeutic intervention, more than 25 percent of infants and parents are likely to suffer significant short-term and long-term post-traumatic stress symptoms, which adversely affect much of a young child's early development.

Cardiac anomalies occur in approximately 1 percent of births. For parents whose babies are hospitalized for cardiac surgery, the rates of acute-traumatic stress symptoms are as high as 40 percent of mothers and up to 25 percent of fathers, half of whom still have these distressing symptoms a year later (Franich-Ray et al., 2013).

Now we have ways of identifying very young children who also experience post-traumatic stress syndrome because of their illness and treatment. To effectively reach these patients, we need techniques and methodologies that enable us to sensitively enter their distressed inner worlds. With this book, Keren and Tortora build on the work of Donald Winnicott, Daniel Stern, and many others who have led us straight into the mind of the infant and very young child.

This is why this book is so important. It is an amazing collaboration between an infant psychiatrist, Keren, and a dance/movement therapist, Tortora, two psychotherapists who help us enter the emotional world of the very sick young child and their parents. It is also a collaboration between the field of early interactional neurodevelopment and infant mental health and that of dance/movement therapy, led by the authors, talking and moving as if in a dance together. This is a book in which the importance of the integration of developmental psychopathology, science, and therapeutic compassion is made abundantly clear.

The clinical science of a human infant's emotional, social, regulatory, and relationship development, particularly the infant's psychophysiological response to trauma, is thoroughly enunciated by Keren throughout this book, carefully interdigitated with vivid clinical vignettes and substantiated research. Tortora demonstrates how the "preverbal" infant does have language and communicates through her body. Instead of articulate spoken words, she expresses herself through the sound of her voice; through her gaze; through hands, feet, and whole-body movements; and exquisitely timed body-to-body, person-to-person interactions. This capacity for intentional communication by infants starts at birth (Trevvarthen, 1998).

The other key component of the baby's language is his capacity for play, even when very ill. Dance/movement psychotherapy can take us into this world of interpersonal communication from the very beginning. Even in the face of severe illness and possible death, it is important for the therapeutic network around young children and their parents to reinforce sensitive, attuned relationships and secure attachments. Worldwide, there have been amazing therapeutic developments that draw on dance, music, drama, and other creative arts to provide young children in the hospital

with opportunities to express their feelings, and to feel in charge of their own bodies and relationships despite serious illness. Using the underpinning concept of “Embodied Parenting,” Tortora describes how parents can respond to their baby’s nonverbal cues, and how the baby can read the parents’ communicative intention. Even in a hospital, the therapeutic dance ensues. Tortora describes ten components of her DANCE assessment tool, and from these components, we can draw inspiration and direction for the dance interaction in our day-to-day in-hospital work with infants and parents.

I was privileged to meet an 18-month-old boy and his mother after a necessary cardiothoracic surgical intervention, when he was found to have significant weakness over the left side of his body because he’d had a stroke. It wasn’t clear how his recovery might progress, but my colleague and I joined him and his mother in conversation, at a measured distance. While we spoke, the boy gazed very intently and anxiously at us, as if to make sure we weren’t going to cause him distress. After a little while, he seemed less anxious, and we engaged in some play with a tuneful rattle. He could not move his left side, but with his right forearm, despite the bandages and a splint that held his intravenous in place, he joined in our game, awkwardly but with purpose, moving his arm to firmly hit and sound off an array of bells on a handle that I placed within his reach. There was a real musicality to the rhythm of his arm movements and the resulting sound as he triggered the bells. His right leg moved as well, and he let me touch his toes while we spoke. He repeated this game over and over, his face softening, his expression lightening, almost becoming a smile on several occasions. The boy tenaciously held my gaze throughout and seemed very pleased and proud of what he could do to the bells with his arm and our connectedness. I think his mother, who had smiled, was also proud.

As my colleague and I reviewed the interaction with the boy, the DANCE assessment tool provided a clear framework for us to better understand what had been happening: how he moved his body; how he responded to our vocal and physical entreaties, and our touch. We had seen him enter into the rhythm of the interaction and our “co-regulated” game. Nestled comfortably and safely in his mother’s arms, he seemed pleased that he could use his right arm. The game we played brought us closer within the “embraced space,” a connection within interpersonal contact that he might otherwise have experienced as threatening.

Although the infant and young child experiencing a serious or life-threatening illness may specifically require the immense talents of a dance/movement psychotherapist, there is so much we can all take from Keren and Tortora’s work into moment-to-moment interactions with such stressed babies and parents. We clinicians can use the fluid, interactional qualities of dance and musicality ourselves in how we speak, respond, hold, touch, and are present with the child and parents, all while being empowered to

initiate seriously playful interaction. Our task is to balance the gravity of the situation for the very young child facing severe illness with that of keeping alive the child's spiritedness and human engagement.

Associate Professor Campbell Paul
Consultant Infant Psychiatrist
The Royal Children's and Royal Women's
Hospitals and the University of Melbourne
President of the World Association for Infant Mental Health

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The development of the work described throughout this book began in 2002, when I, Suzi Tortora, was encouraged to apply to start a pediatric dance/movement therapy program at Memorial Sloan Kettering Cancer Center (MSK) in New York City. This new program, the first of its kind for MSK, was established with funds raised by the nonprofit Andréa Rizzo Foundation, then only several months old. But the genesis of the idea for a program was years before that, through Andréa Rizzo, a gifted dancer, special educator, and herself a survivor of childhood cancer. It had been her dream to give back to MSK, the place where she was healed as a baby. The untimely and tragic loss of Dréa, and the deep love from her family and friends, became the impetus to start the foundation and bring life to her passionate dream. Now, so many years later, Dréa's Dream, a dance/movement program specifically for children with cancer and special needs, is thriving at MSK and hospitals and schools across the United States. My profound thanks go to Dréa's Dream founder and president Susan Rizzo Vincent; countless volunteers, friends, and family members for their unwavering support and dedicated work; and to all the dancers, dance schools, and others who raise and provide funds to support this organization. Following their lead, a portion of the proceeds from this book will go to the Andréa Rizzo Foundation (www.dreasdream.org/).

The opportunity to start a medical dance/movement therapy program at MSK Kids, the pediatric oncology program at MSK, has been an honor and privilege that no words can truly convey. My work at MSK Kids has been fueled by the commitment and passion of doctors, nurses, the pediatric administration, psychiatry, child life specialists, integrative medicine practitioners, and all the staff, who give so much of themselves each day. Unfortunately, there is not enough room here to name every individual, but the following people have been especially instrumental in supporting the dance/movement therapists as we work together each day: Latisha Jones was the first nurse to invite me to join her work with a patient and his family in distress during a treatment; pediatric oncologist and researcher Dr. Nai-Kong Cheung was an early advocate of our work in

helping pediatric patients and their families during immunotherapy treatments; pediatric oncologist Dr. Brian Kushner's spirited participation in our play turns any treatment into a dance party, immediately putting the patient and family at ease; Dr. Shakeel Modak, whose understanding of the value of this practice is evident in the opportunities he has given me to present the work to the medical team, and his introduction and recommendation of our support to families starting immunotherapy treatments; and all the multiteam discussions and collaborations across disciplines with child life specialist Jessica Anenberg, psychologist Dr. Laura Cimini, and psychiatrist Dr. Julia Kearney who have been instrumental in supporting our youngest patients and their families.

I am also indebted to our team of extraordinary integrative medicine practitioners: chief of integrative medicine Dr. Jun Mao's positive energy encourages all of us to continue to be innovative; Eva Pendleton, associate director of integrative medicine, has been my manager and friend, offering guidance with kindness and clarity; Dr. Nirupa Raghunathan, director of pediatric integrative medicine, always finds time to discuss treatment strategies and stimulates our whole team effort; music therapists Karen Popkin and Holly Mentzer, both friends and colleagues, whose spontaneous, live musical creations add a sensitive and thoughtful element to our co-treatments; Jane Greene, massage therapist and integrative medicine program coordinator, for her always thoughtful conversations; Dr. Jocelyn Shaw, the first dance therapy intern at MSK Kids, who then became my dance therapy colleague, helping to build the dance/movement therapy program in the early years; and Jennifer Whitley, my current dance therapist colleague, whose brightness, warmth, skill, and innovation make her an invaluable asset to all our programs at integrative medicine. I also thank my longtime friend and colleague, dance therapist Dr. Nancy Bear-dall, who has been a sounding board for all of my ideas during my whole career.

This book would not have been possible without the trust of all the young children and families Miri Keren and I have treated. We offer a special acknowledgment to each one of them, from the more than 40 years we have been privileged to work in medical and private clinical settings, with families from around the world. Finally, but not least of all, we thank our colleagues, friends, and family members who have taken the time to read many versions of our manuscript: Dr. Theodore Gaensbauer, whose advice, skill, and deep knowledge of trauma and young children have been invaluable throughout our writing process; Dr. Campbell Paul, who has provided sincere and generous support of our work, including the foreword to this book; Paul Bonnar, for his abiding editing, tech, and moral support; and Grant Collier, multimedia artist, whose beautiful and sensitive eye has added heart to our images. And, of course, our thanks go to Amanda

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Introduction

Daniella, age nine months, is reeling. Screaming and thrashing her tense body to and fro, she is protesting, as best as she can, the attempts of her two nurses to draw yet another blood sample. Mom is at her bedside, talking in a controlled yet anxious manner, trying to coax Daniella to calm down. Time is running out. This blood needs to be drawn now and, after their third attempt, the nurses are losing options because Daniella's small veins keep collapsing. The tension in the room is palpable. I enter at this moment, and Mom and the nurses look at me with relief. I know Daniella and her mother well, for we have been dancing together since they first started treatment for medulloblastoma three months ago. After quickly assessing the situation, I put on Daniella's favorite song, "Twinkle, Twinkle, Little Star." Mom starts to sing along as she picks up Daniella, rocking side to side. We all join in, gently swaying our bodies, quietly singing too. This dancing-lullaby interlude resets the room. As Daniella settles, snuggling into Mom's arms, the nurses are now able to carry out the procedure smoothly.

This opening vignette describes a typical dance/movement therapy (DMT) intervention used to support a parent and her infant with complex medical needs, while enabling the nurses to complete a medical procedure. This level of collaboration between the patient, family, and medical team is very common in the pediatric oncology setting where Tortora works, and DMT is part of integrative medicine holistic health services.

Our discussion begins with integrative medicine because it is foundational to the approaches described in this book. Integrative medicine brings evidence-informed complementary and conventional medicine together in a coordinated manner. This approach is a more recent development in health care, focusing on practices that promote psychological, mental, physical, and spiritual health for the whole family during all stages of treatment (NIH-NCCIH, 2021). In 2017, the Society for Integrative Oncology (SIO) formed a special interest group of international professionals in pediatric oncology to advance understanding of the field. The definition this group created to describe pediatric integrative oncology

underlies the principles discussed throughout this book: Pediatric integrative oncology} is

a relationship-centered, evidence-informed, personalized approach to the whole child and family system utilizing mind and body practices, natural products and/or lifestyle modifications alongside conventional oncology care. Pediatric integrative oncology is offered throughout the illness trajectory to optimize health and wellness, enhance healing, minimize suffering, improve quality of life, and empower children and families to become active participants before, during, and beyond cancer treatment. (Tortora et al., 2021, p. 1)

The focus on whole person health – to improve and restore each individual’s overall health rather than focusing solely on the disease and its symptoms – is especially important when working with a particularly vulnerable population: families with infants and young children who have complex medical conditions. How often do we hear the statement “Don’t worry; babies are too young to remember and understand” in an attempt to soothe distraught parents during a difficult procedure? What if this is not true? What is the baby’s emotional experience during repeated medical interventions, and what impact might this have on their development? How can we best support the emotional and social development of an infant or young child when there is an overwhelming, potentially life-threatening, medical condition that rightfully takes center stage?

Infant mental health research informs us that loving, secure relationships act as a stabilizing buffer during stressful encounters. But medical illness in early childhood affects the whole family. It is challenging for parents to maintain a healthy, loving relationship with their baby when confronted with such complex stresses as assisting in invasive medical procedures, understanding their baby may grow into a child with long-term difficulties, and the potential death of their baby (Melamed, 2010).

This book presents the application of DMT in pediatric medical settings to address these questions, focusing on how to approach the seemingly impossible juggle that is necessary to keep the baby’s medical needs and emotional and felt experiences in mind, while also supporting parents through this life-changing journey. The foundational principles of pediatric medical DMT focus on the young child’s embodied experiences and their manifestation in the child’s behaviors and family dynamics, from the perspective of nonverbal interactional and relational experiences. DMT’s focus on the body as an expressive tool for intervention uniquely addresses both the psychic and somatic aspects of the infant’s experience of illness. Integral to this method is the use of nonverbal analysis to observe the qualitative elements of the infant’s movement style to understand the baby’s cues and preverbal experience.

DMT supports the infant/child's emotional life during the medical experience, taking into consideration subtle and more obvious effects on the child's later emotional and social development and other behaviors. DMT strives to establish a safe environment that enables the young child and family to share their emotional responses and manage difficult medical procedures, while creating and preserving loving, playful early childhood experiences and memories.

Infant mental health research reveals that babies do perceive their environment and remember adverse experiences (Gaensbauer, 1995, 2002, 2011). Early perception is registered through the baby's bodily felt experience, perceived through multisensory experiences, and informed by loving, secure interactions with primary caregivers (Gaensbauer, 2004). The "felt experience" refers to embodiment, which is a foundational concept used throughout this book. In brief, "embodiment" refers to the dynamic relationship that exists between perception, action, and emotion as experienced and expressed through unique, personal, nonverbal actions (Koch & Fischman, 2011; Sheets-Johnstone, 2011). It is only recently that more hospital programs are considering how the felt experience of having and being treated for an illness so early in life may affect the young child's current and future mental health (Kroupina & Elison, 2019; Lee et al., 2021; Zero to Three, 2016). The focus on embodiment is now a guiding principle used in DMT for intervention (Koch, 2006).

This notion of embodiment correlates to Stern's concept of body self (Stern, 1998), that is, in turn, very much related to the processes of self-development in the first years of life. Furthermore, parental embodiment is perceived by the infant and conveys vital cues to the parent's emotional stance, becoming a major component of the early parent–infant relationship. The quality of the parent–infant relationship and the family's emotional communication is at the core of mental health from infancy to adulthood (Sroufe et al., 2005). Pediatric life-threatening illness, a traumatic event for parents and infant, often derails the course of this growing relationship. Very young children "behave" their emotional distress rather than talk about it. So the role of child psychiatry at pediatric hospitals is to reflect with the parents on the link between their child's and their own behaviors during the traumatic event, articulating what the child and parents sense but often find unspeakable (Lieberman & Van Horn, 2008). Mothers who reported more difficulty in recognizing and understanding their child's mental states displayed decreased tolerance of distress on behavioral and self-report measures (Rutherford et al., 2015). Hence, facilitation of the parental reflective stance (Slade, 2005) to support increasing the awareness of parents and the psychiatry team of the infant's nonverbal communication is very much needed in these distressing medical situations. Adding the dance/movement therapy lens helps the caregivers and the whole medical team to read and understand the child's unique nonverbal

communications. This empowers both the parent's and the child's senses of agency and control. The enjoyable activities in a dance/movement therapy session provide supportive ways to engage and strengthen their growing relationship, finding expression for these experiences that are difficult to articulate in words.

Goals of This Book

The idea for this book evolved out of years of dialogue between the authors, who both have specialties in infant mental health, to better support families and their children with medically complex conditions, and the medical teams that work so attentively with them, and to bring this knowledge to a wider audience. The lens of a child psychiatrist, Keren, provides a more thorough view into the family dynamics, including intervention strategies to support healthy development and prevent later emotional and behavioral disturbances. Collaborating with a dance/movement therapist who also has expertise in nonverbal communication analysis, Tortora, adds an in-depth awareness of the unspoken needs often expressed through subtle and overlooked cues. We share the belief that psychic and somatic processes are interwoven, and we have worked together for many years on the nonverbal aspects of communication between parents, infants, and therapists. The idea of focusing on how to alleviate the distress of very young children who are severely ill and to prevent the long-term sequelae of traumatic experiences on a child's mental health emerged from these years of collaboration. Further examples of our joint thinking are shared in the clinical discussions that follow the vignettes in each chapter.

This book also demonstrates how to build a treatment plan based on the infant or toddler's embodied experience, within the context of treating the whole family system during the medical experience (Tortora, 2019). The emotional and social strengths and weaknesses in each member of the family are considered within the context of the whole environment. This book fills a gap in the literature, for it introduces a pediatric treatment approach that – at its core – focuses on the very young pediatric patient's felt experience as it manifests in the child's behaviors and the family relational dynamics. By placing the primary focus on the messages our bodies speak, it gives voice to those aspects of the medical experience that have no words. This innovative approach to healing brings together a variety of fields, including infant mental health, infant and child psychiatry, nonverbal-movement analysis, somatic psychology, and the creative arts therapies. Evidence-based research from these professions is used to inform the clinical practices discussed in this book.

Our hope is that this book will stimulate much-needed future research, for there is a great sparsity of research in medical dance/movement therapy and no research specifically in pediatric dance/movement therapy with