

After the Music: A Workbook for Music Therapists
Working with Terminally Ill Children and Adolescent Patients

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Abstract

Many music therapists are members of hospice and palliative care teams, supporting the physical and psychosocial needs of patients and their families. However, working in this type of setting, especially with terminally ill children and adolescents, may lead to risks of burnout, compassion fatigue and disenfranchised grief. Music therapists are put into a unique role, needing to be both open and supportive while remaining self-aware and professional in our positions. This author examined related articles, books and models that focus on the risks of working in this type of environment. In response to the existing literature, this author created a workbook designed for music therapists working with terminally ill children and adolescents. My hope is that this workbook will provide helpful information and concrete exercises to prevent burnout and address compassion fatigue, increasing the professional's emotional intelligence and overall job satisfaction and retention.

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To the patients and families whom I have cared for, I am honored to be a part of your journey. In times of joy and times of sorrow, you have helped me grow as a therapist. When only their names remain, let us remember them.

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Introduction

Death is an inevitable part of the human experience. “Whether it is intense feelings of loss and grief generally associated with the death of a loved one or the ultimate confrontation with one’s own mortality, many people fear the dying process” (Groen, 2007, p.90). Music therapists working with patients who are terminally ill often experience forms of professional loss and resulting compassion fatigue after the death of a patient (Love, 2007; Parkes, 1997). The long term *cost of caring* may result in emotional exhaustion, depersonalization, and ineffectiveness in one’s clinical practice (Vachon, 2011; Love, 2007). Research suggests that the loss of a patient can elicit emotions resembling secondary traumatization, leaving a lasting impression on one’s ability to provide empathy to those being cared for. Furthermore, working with terminally ill children and adolescents may cause frustration and distress for healthcare professionals as “they observe children struggling against formidable odds and parents grappling with some of the most difficult decisions a family can ever confront” (Rushton & Ballard, 2011, p. 310).

Professionals facing grief and compassion fatigue may experience an array of debilitating emotional, cognitive, physical, behavioral, and spiritual complications. These often include: feelings of hopelessness and powerlessness, difficulty concentrating; changes in appetite, decrease of physical activity and a questioning of one’s spiritual beliefs and values (Love, 2007). This gradual change can lead to ineffectiveness in one’s clinical practice, frequent job changes and a long-term, decreased capacity for intimacy (Wenzel, 2011).

Limited literature is available that specifically addresses music therapists working through grief or compassion fatigue. Even when looking to similar health care disciplines, there appears to be a lack of concrete and practical exercises or interventions for processing the loss of

a patient. These texts often briefly describe symptomology congruent with these experiences, only emphasizing the difficulties experienced when working with the terminally ill. Specifically, they describe the fast-paced environment that accompanies working in the medical community and the stressors it may place on the healthcare professional.

It appears as though a stigma exists that surrounds the grief that professionals may experience when working with the dying. Health care professionals often remain with patients at their most vulnerable times. However, these same professionals are often taught to exhibit an unaffected demeanor following patient deaths. This stigma leads to a phenomenon referred to as “disenfranchised grief” (Spidell, 2011, p. 76). Individuals experiencing disenfranchised grief are at a greater risk for utilizing maladaptive coping behaviors. “Their grief tends to become hidden, poorly expressed and unprocessed” (Spidell, 2011, p. 84). In other words, healthcare professionals may have the tools or supporting literature to understand that they are experiencing compassion fatigue or disenfranchised grief without the necessary preventative and restorative tools and coping skills.

Many music therapists work with terminally ill patients. Wenzel (2011) states that working with the dying can be very emotionally draining work. Music therapists in such settings often deal with their own grief due to patients’ deaths (Marom, 2008). In addition, working with children and adolescents who are suffering increases the burden on health care professionals for both personal and professional reasons (Rushton & Ballard, 2011). Little literature is available to address emotional needs and possible countertransferences that arise when working in this population. The purpose of this clinical project is to create a workbook that supports music therapists who work with terminally ill children and adolescents through concrete exercises and interventions that support positive coping and prevent compassion fatigue.

Definitions:

Burnout can occur as the result of negative stressors in the work environment. When incongruences exist between personal or professional values and that of one's place of work, the risk of burnout is increased. Burnout may also be caused by large or unmanageable caseloads. It is characterized by symptoms including poor judgment in clinical decision-making, boundary violations with patients and families, as well as a questioning of one's clinical skills (Rensenbrink, 2011).

Compassion fatigue is often referred to as the "emotional cost of caring for others" (Hilliard, 2006; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011, p. 173). It is characterized by physical and emotional difficulties that may include instances of headaches, stomachaches, irritability, hopelessness and disruptions in sleeping patterns (Love, 2007; Redinbaugh, Schuerger, Weiss, Brufsky, & Arnold, 2001; Wenzel, Shaha, Klimmek, & Krumm, 2011). Long-term experiences with compassion fatigue are often congruent with instances of burnout, leading to "high turnover rates, job-related errors, and lower patient satisfaction rates as well as feeling emotionally compromised" (Hilliard, 2006, p. 395).

Disenfranchised grief is a phenomenon experienced by health care professionals working with the terminally ill. It is a complication of grief that arises when excluded from the process of mourning after the death of a patient. Our Western model of professionalism "rests on foundations of a biomedical approach, rational detachment, and objectivity. A widespread belief exists that emotional detachment is a necessary defense when witnessing the suffering of patients" (Rensenbrink, 2011, p. 44). These undertones in the medical community may further discredit any feelings of loss and/or sadness experienced following the death of a patient. Due to the lack of community support, medical staff may feel excluded from expressing these feelings

of loss and grief associated with a death (Spidell, Wallace, Carmack, Noguera-Gonzalez, & Cantor, 2011).

Music therapy is the “clinical and evidenced-based use of music interventions to accomplish individualized goals within a relationship by a credentialed professional who has completed an approved music therapy program” (American Music Therapy Association, n.d., para. 1). Music therapists are often a part of a patient’s larger interdisciplinary team. Through individualized music interventions and the relationships that develop through them, music therapy in pediatric, palliative care has the potential to provide comfort, relieve distress or pain and promote family support (Lindenfelser, 2014).

Purpose Statement

Healthcare professionals have a greater risk of experiencing compassion fatigue and burnout as a result of their work environment (Doka, 2002; Douglas, 2010; Fetter, 2012; Granek, Krzyzanowska, Tozer, & Mazzotta, 2012; Melvin, 2012; Rushton & Ballard, 2011; Spidell et al., 2011). Feelings of loss associated with the death of a patient may further be exacerbated when patients are children or adolescents. Music therapists working with this population are put into a unique role, needing to be both open and supportive to the patient, while remaining protective and emotionally guarded in order to sustain a long-term practice (Spidell). The intimacy often shared between patients, families and music therapists through music making is then unacknowledged by the community after death. Due to the repetitive nature of many of these stressors, many health care professionals are at significant risk of developing burnout and/or compassion fatigue

Even with the serious repercussions that may occur as a result of long-term practice, no practical workbook exists to help music therapists acknowledge and work through loss and

grieving. While this is not considered a standard or uniformed way of coping among health care professionals, the creation of a workbook may support positive coping, increase personal resiliency and decrease burnout and compassion fatigue. The purpose of this clinical project is to provide a workbook for music therapists working with terminally ill children and adolescents. The author aims to provide helpful information and concrete exercises to prevent burnout and address compassion fatigue, increasing the professional's emotional intelligence and overall job satisfaction and retention.

Literature Review

End of Life Care

“Medicine and public health have transformed the trajectory of our lives” (Gawande, 2014, p. 25). This continuous advancement of modern medicine has not only changed the way we live but also the ways we die. It is estimated that today, 25% of United States citizens are involved in end-of-life care in long-term treatment facilities (National Hospice and Palliative Care Organization [NHPCO], 2014). This type of care encompasses a variety of illnesses and diseases, both chronic and acute in nature. For some, end-of-life care may mean prolonging life by any means possible. Others may be more focused on comfort measures and quality of life.

End-of-life care provides opportunities for patients to have options. Through discussion, patients are able to make decisions regarding final wishes including advanced directives and where they wish to spend their time left. This type of care creates a context where patients and families can experience a sense of closure, choosing to participate in either hospice or palliative care. Patients involved in both hospice and palliative care early may also experience a prolongation of life (Temel et al., 2010).

Hospice

Each year, 1.5 million people receive hospice care in the U.S. (National Hospice and Palliative Care Organization [NHPCO], 2010). “Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes” (NHPCO, 2014, p. 3). This program is intended for people at the end-of-life. It offers interdisciplinary support to address the patient and family’s need for physical and psychosocial care.

Rather than focusing on curative measures, the primary goal of hospice care is promote comfort and the highest quality of life possible (Mayo Clinic, 2013). Patients involved in hospice care are expected to live six months or less. If the patient survives beyond six months, they may continue to receive this type of care if their doctor believes their prognosis remains imminent (Medicare, n.d.; Mayo Clinic, 2013). While hospice was initially developed to care for patients with cancer, it is now available to support individuals with a variety of life-limiting illnesses (Mayo Clinic, 2013; National Hospice and Palliative Care Organization [NHPCO], 2010).

Palliative Care

If the patient does not meet all of the qualifications for hospice support, they may elect to start or continue with palliative care. Palliative care is support for patients experiencing pain or other symptoms as a result of a serious or life-threatening illness (Center to Advance Palliative Care, 2012). Patients may begin palliative care due to (a) a life-threatening condition where curative treatment is possible, (b) conditions where death is expected but may be able to be prolonged with long-term treatment, (c) progressive illnesses without curative treatment, focusing more on comfort measures or (d) irreversible conditions that are not progressive but lead to potential complications and likelihood of a premature death (Lindenfelser, 2014).

The palliative care team communicates and coordinates with the patient's doctors in order to promote pain and symptom management. These care providers are also qualified to offer emotional and psychological support to patients and families as they undergo treatment. Unlike hospice, patients may still be aiming for curative measures while receiving palliative support (Center to Advance Palliative Care, 2012).

Children and Adolescents

“Working with dying patients of any age is challenging, and working with dying children can be even more taxing” (Sluzewski, 2011, p. 48). Working with children and adolescents who are terminally ill requires specialized skills and training (Lindenfelser, 2014; Rushton & Ballard, 2011; Maue-Johnson & Tanguay, 2006; Groen, 2007). Providing *family centered care*, especially in the pediatric setting, is essential for the best working relationship between patients, families, and medical staff (Bluebond-Langer, 1980; Lindenfelser, 2014; Pavlicevic & Wood, 2005). Family centered care centers around four core concepts: (a) dignity and respect for the patient and family, (b) information sharing, (c) involvement and (d) collaboration with family members (“Family centered care,” 2015). It requires patience, empathy, and a commitment from the medical team to create trust and rapport during such a difficult time. Interdisciplinary teams working under this model ensure that the patient and family are provided the physical and psychosocial support they require.

“Suffering and loss are intrinsic and inevitable dimensions of caring for children with life-threatening conditions” (Rushton & Ballard, 2011, p. 315). This is exacerbated by the stigma that surrounds the concept of children requiring palliative or end-of-life care (Bluebond-Langer, 1980; Pavlicevic & Wood, 2005; Lindenfelser, 2014). “The death of a child poignantly underlines the impact of social and cultural factors on the way that we die and the way that we permit others to die” (Bluebond-Langer, 1980, p. 231). As a result, children with life-threatening and/or limiting conditions are often prescribed aggressive treatment options, aiming for prolongation of life at all costs (Lindenfelser, 2014). These aggressive treatments can put great financial strain on families who are already burdened emotionally and spiritually from diagnosis. During these difficult times, music therapy has the ability to make a true impact on the hospice

community due to its ability to develop meaningful relationships and be flexible in meeting the patient's needs and promoting an overall quality of life.

End of Life Care Providers

The hospice interdisciplinary team may be comprised of a variety of health care professionals. Common disciplines include doctors, nurses, chaplains, social workers, and expressive therapists (Bright, 2002; Groen, 2007; Maue-Johnson & Tanguay, 2006). Patients in hospice care require support for both physiological and psychological needs. Medical professionals including doctors and nurse practitioners are consulted to provide comfort measures and decrease the physical symptoms associated with death such as pain or respiration difficulties.

However, patients and family often benefit from psychosocial support as well. Social workers may be consulted to help families make important decisions, such as instating an advance directive or beginning the funeral planning process. Chaplains seek to address the religious and/or spiritual needs of their patients and families. In situations where a patient is critically ill or dying, the chaplain can serve as an advocate and spiritual guide (Spidell et al., 2011). Child life specialists are available to support the patient and family in understanding and coping with their diagnosis. They may support the patient during an invasive medical procedure or to become more comfortable around medical equipment. Bereavement coordinators provide support to families after a patient has passed away, helping plan the funeral and identifying counseling services available. Creative arts therapists, too, play a role, providing opportunities for expression and promoting a greater quality of life.

Loss, Grief, Compassion Fatigue in Healthcare Providers

Health care professionals providing care to patients who are terminally ill may experience a great deal of stress (Hildebrandt, 2012; Lorenzato, 1999; Marom, 2008; Spidell, Wallace, Carmack, Noguera-Gonzalez, & Cantor, 2011). Those who continuously face the loss of patients often experience physical and emotional difficulties that can persist over time (Melvin, 2012). Common themes that cause stress for professionals include: (a) limitations of care and medicine, (b) team contributions, (c) timing and withdrawal of care and (d) overall responsibilities of providing end of life care (Pattison, Carr, Turnock, & Dolan, 2013). The pressure and responsibility of being involved in a patient's journey can lead to compassion fatigue and manifestations of grief.

“Compassion fatigue is often referred to as the emotional cost of caring for others” (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011, p. 173). Those who experience this phenomenon often exhibit physical and emotional symptoms. Physical symptoms may include headaches, weight changes, stomachaches, noise intolerance and restlessness. Psychological symptoms may include anxiety, depression, apathy, feelings of hopelessness, and the reevaluation of core, spiritual beliefs (Fetter, 2012; Love, 2007). Compassion fatigue can manifest from states of grief and/or bereavement (Love, 2007; Spidell et al., 2011). Grief is a natural response to experiencing a loss; however, the amount of death healthcare professionals typically see may lead to complicated or disenfranchised grief.

Grief is “essentially an unavoidable human experience that becomes increasingly prevalent with age” (Parkes, 1997, p. 47). All persons experience grief at some point in life. It is a normal reaction to undergoing some form of loss. Common domains of grief include: (a) emotional, (b) cognitive, (c) physical, (d) behavioral, and (e) existential manifestations (Love,

2007). Grief indicators are experienced most acutely following the loss. In normal grief patterns, they dissipate on their own without outside intervention.

Typically, if an individual continues to experience acute symptoms of grief for longer than six months, it is considered complicated grief (Love, 2007). Complicated grief is seen as a form of maladaptive coping. While every individual experiences and copes with loss differently, a variety of risk factors can arise that may provoke complicated grief patterns. These include (a) lack of adequate coping mechanisms, (b) previous experience of trauma or loss, (c) an absence of community support, and (d) further losses or bereavements (Love, 2007, table 1). These particular indicators can often be a part of the healthcare professional's work environment when working with serious or terminally ill patients.

The medical community, as a whole, does not adequately support professional grief and bereavement in the workplace (Spidell et al., 2011; Granek, Krzyzanowska, Tozer, & Mazzotta, 2012; Melvin, 2012; Wenzel, Shaha, Klimmek, & Krumm, 2011). Disenfranchised grief is common in healthcare professionals, as society does not recognize the relationship with patients, does not acknowledge the loss, and excludes the professional from grieving. This lack of acknowledgement regarding loss can lead to a depersonalization of the work, low energy, isolation and self-destructive behaviors (Spidell et al., 2011).

In order to counteract the effects of patient loss, healthcare professionals benefit from the development of individual coping strategies, community support, and a mutually supportive work environment (Rushton et al., 2006; Wenzel et al., 2011). When experiencing disenfranchised grief, there is a greater risk of developing isolated feelings. A positive correlation was shown between the instillation of bereavement debriefings and the resiliency of healthcare workers (Rushton et al., 2006). Furthermore, creating a mutually supportive

environment with spaces for staff to practice self-care may promote long-term staff retention (Wenzel et al., 2011). As more music therapists begin to provide end-of-life care, this profession too, can benefit from tools for increased self-awareness, processing and individual therapy.

Music Therapy

Music therapists are commonly members of hospice and palliative interdisciplinary teams (Dimaio, 2012; Groen, 2007; Maue-Johnson & Tanguay, 2006; Pavlicevic & Wood, 2005; Runningdeer, 2013). Music therapy is defined as “the clinical and evidenced-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program” (American Music Therapy Association, 2013, para. 1). Board-certified music therapists utilize music to promote quality of life and emotional expression in hospice and palliative care (Bright, 2002; Dimaio, 2012; Marom, 2008; Pavlicevic & Wood, 2005; Runningdeer, 2013).

Patients in hospice and palliative care may experience psychological and physiological benefits when receiving music therapy services (Dimaio, 2012; Groen, 2007; Maue-Johnson & Tanguay, 2006; Pavlicevic & Wood, 2005; Runningdeer, 2013). Music can often provide a refocus from pain and anxiety. Non-pharmacological pain management decreases the risk of opiate dependency and/or overdose (Bright, 2002). Utilizing music that is familiar to the patient and family often provides a sense of comfort and normalcy. Music therapists may create more relaxing music to encourage deep breathing and the continued development of positive coping skills (Pavlicevic & Wood, 2005).

Relationships that are developed through music therapy can play an impactful role in end of life care (Runningdeer, 2013). Through these relationships, patients feel more comfortable engaging in opportunities for emotional expression and life review (Runningdeer, 2013; Maue-

Johnson & Tanguay, 2006). Music therapy can provide quality of life by (a) honoring a person's identity and self-worth, (b) providing the chance to engage in a meaningful relationship, (c) offering the opportunity to engage in a mentally stimulating activity, and (d) having something to look forward to (Bright, 2002).

In order to provide highly individualized care, a variety of music therapy interventions may be utilized. Common interventions in hospice care include music listening, songwriting and recordings for memory/legacy building (Bright, 2002; Dimaio, 2012; Pavlicevic & Wood, 2005; Runningdeer, 2013). Creating recordings of patients in hospice and palliative care can "create something that can preserve the humanity of a situation" (Cincinnati Children's Hospital Medical Center, 2014). Engaging in music therapy can be a deeply personal experience. This may strengthen the relationships between the music therapist, patients and their families (Pavlicevic & Wood, 2005; Runningdeer, 2013).

The intimacy that music therapy can provide may heighten the feelings of loss for music therapists who work in end-of-life care (Lorenzato, 1999; Pavlicevic & Wood, 2005). Even after being involved in such an intimate *musical space*, music therapists are often excluded from the grieving process and encouraged to exhibit *emotionless professional behavior* (Spidell et al., 2011). This may mean hiding how one personally feels about a patient's death when interacting with the family or perhaps, refraining from attending a patient's funeral. Some literature is available that addresses the health-care professional's grief. However, it is only recently that research has been created to address the music therapist's unique experiences (Sluzewski, 2011; Lorenzato, 1999; Kim, 2012). Furthermore, little to no practical suggestions existing in terms of processing that are uniquely tailored to practicing music therapists. This can lead to situations of compassion fatigue and grief, affecting his or her ability to practice efficiently (Fowler, 2006).

Purpose Statement

Often music therapists work with many populations including terminally ill children and adolescents. Wenzel (2011) states that working with the dying can be very emotionally draining work. These feelings may be exacerbated when experiencing the death of patients so young, as our society treats this as a taboo subject. Furthermore, music therapists in such settings often deal with their own grief due to patients' deaths (Marom, 2008). Little literature is available to address emotional needs and possible countertransference that may arise when working with the terminally ill. The purpose of this clinical project is to provide a workbook for music therapists working with terminally ill children and adolescents. The author aims to provide helpful information and concrete exercises to prevent burnout and address compassion fatigue, increasing the professional's emotional intelligence and overall job satisfaction and retention.

Methods

Design

A workbook was created that addresses professional grief in hospice music therapists. The author hopes this workbook will provide helpful information and practical exercises to develop positive coping skills and process grief through healthy behaviors. This workbook is geared towards music therapists working with pediatric patients with terminal illnesses. In order to be the most readily available to these professionals, the final, published project will be an e-book available for download.

Procedure

The author reviewed literature pertaining to grief in the workplace and the potential symptoms associated with compassion fatigue and burnout. The author identified literature that determines the emotional, environmental, and social stressors of working in an environment with dying persons, particularly children and adolescents. By understanding possible manifestations of grief and how they may occur in the medical setting, this author was better able to create a workbook that addresses the difficulties of working with terminally ill children and adolescents.

Following a review of literature and existing assessment instruments, the author created an assessment tool, utilized to measure compassion fatigue and burnout. This will allow individuals to assess their need for further self-care practices and/or processing techniques. Following the identification or creation of an assessment tool, the music therapist will explore broad areas that appear important in preventing disenfranchised grief and compassion fatigue, such as creating a mutually supportive environment.

Education on different types of grief, compassion fatigue and burnout will also be provided in order to help music therapists better identify their own feelings and place in their

work with terminally ill children and adolescents. Concrete examples that are provided were collected and applied in the workbook. By compiling and subsequently creating self-care techniques and exercises for processing, the workbook will hopefully encourage music therapists to find a sense of closure while maintaining proper boundaries. A variety of these tools will be provided to address different coping strategies.

Evaluation

At least two board-certified music therapists working with terminally ill children and adolescents will evaluate this e-book. They will be asked to read through the material and utilize any worksheets or exercises/interventions. Once their feedback is collected and compiled, any needed revisions will be made in the final version of this e-book.

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Young Life Cut Short

By: Author Unknown

Do not judge a song by its duration

Nor by the number of its notes

Judge it by the richness of its contents

Sometimes those unfinished are among the most poignant...

Do not judge a song by its duration

Nor by the number of its notes

Judge it by the way it touches and lifts the soul

Sometimes those unfinished are among the most beautiful...

And when something has enriched your life

And when its melody lingers on in your heart.

Is it unfinished?

Or is it endless?

Introduction

Compassion hurts. When you feel connected to everything, you also feel responsible for everything. You cannot turn away. Your destiny is bound to the destiny of others. You must either learn to carry the Universe or be crushed by it. You must grow strong enough to love the world, yet empty enough to sit down at the same table with its worst horrors. ~Andrew Boyd

Office, The Playroom Closet, The Bathroom Stall

It is not an uncommon occurrence for me to be approached in the hallway. As I am often toting a guitar, large drums and colorful instruments, my role as the hospital's music therapist is quite the icebreaker. Practicing in the pediatric setting has always been a dream of mine and I feel extremely fortunate to be doing this type of work for a living. However, I would be remiss if I didn't share that my role carries its own shares of sadness and heartache. With many of my patients, I have the privilege of sharing in their last phase of life – their final months, weeks or days through music.

On one particular day, I remember making the long walk through the winding hallways from the ICU to my office. I had just shared the final moments with a patient that I had been working with for over six months. Physically, I felt as though my guitar was twice as heavy on my shoulders and my feet seemed to shuffle, rather than step. The goodbye was difficult and it was clear that the patient was in pain and the family, rightfully distressed. Once I finally made it onto the elevator, an individual smiled to me and said, "You must have the most fun job in the world." It's true. I chose this field because I believe it is important, meaningful *and* fun work. However, at that particular moment, it didn't feel like much fun.

When talking with other pediatric music therapists, nurses, doctors, child life specialists and healthcare professionals, there is a recurring joke that rings true. When you need to cry or if things get too hard, that's the time to hide in your office – in the playroom closet – in the bathroom stall. It seems like an unwritten rule that acknowledging any feelings of loss and grief

or the difficulty of your work somehow negates your sense of objectivity and aptitude to be an effective clinician.

How does one practice long-term and in a meaningful way when keeping feelings “close to the vest” or locked away in that office – that playroom closet – that bathroom stall? My personal observances and current research substantiate that these types of behaviors and potentially self-induced isolation may cause irreparable damage in both one’s personal and professional life. It is extremely meaningful yet challenging work.

Feelings of sadness can also be intensified when experiencing the death of a child or adolescent. It seems unfair and unnatural. They carry a unique wisdom and a bright-eyed outlook on life that can often be lost among the grown-ups of the world. Their honesty and their astonishing sense of resiliency seem to touch our hearts in a special way.

Yes, there are times where we need our hiding places and that playroom closet seems like a personal, safe haven. However, I intend to remain a pediatric music therapist for many years to come. I hope, that like me, you seek opportunities to gain self-awareness, resiliency and emotional intelligence while finding ways to find meaningful ways to reach and connect to the healthcare community.

Why A Workbook?

It is my belief that most music therapists enter into this profession because they find the work meaningful. However, this type of practice is not for everyone. Trying to share the ins and outs of music therapy in pediatric palliative or hospice care with family and friends can be difficult. Not only are there patient privacy laws, namely the Health Insurance Portability and Accountability Act (HIPAA), but because it can be too sad for others to hear. This workbook is intended to provide opportunities for processing and growth, to strengthen resiliency and

emotional intelligence, as well as identify supportive people or groups of individuals from which to seek advice and/or support.

How Do I Use This Workbook?

Each individual copes differently, just like each loss will affect therapists in a unique way. This workbook is intended to serve as an added support or jumping off point in developing meaningful and individualized coping strategies as well as a greater sense of self awareness. No stipulations are placed in how to use this workbook. It can be read and utilized in order or you may choose to jump around to topics and/or exercises that you find interesting or useful. Remember, the more often you take time for your own self-care and processing, the greater sense of resiliency you may experience in your music therapy practice. Here are some helpful suggestions to get you started.

1. When using in this workbook, intentionally set aside at least 10 – 15 minutes as a medical music therapist.
2. Find a quiet and comfortable space.
3. Challenge yourself to try new exercises for processing and self-care in order to deepen your self-awareness and coping skill “tool-kit”.
4. Utilize this book prior to and after patient deaths or difficult moments in your work. Your processing and self-care needs may be different during these times.

Use this workbook in a way that makes sense and is meaningful to you. It’s up to you to decide what that may mean. Remind yourself that when you feel you have the least amount of time for self-care that is when you need it the most!

Risks of the Work

I feel an inherent tiredness that cannot simply be cured by sleep ~Author Unknown

Being with pediatric patients and their parents in such difficult times poses risk for the practicing music therapist. As a member of the psychosocial support team, it is imperative that one learns to be present and empathic while also being somewhat guarded in order to sustain a healthy, long-term practice. As music therapists we understand the process of “musiking” together as an intimate space where we can learn a great deal about patients. However, the medical community does not always provide an atmosphere that supports its healthcare staff. In fact, it may be expected that staff exhibit emotionless, professional behavior in order to be considered successful in their work. Each music therapist’s experiences in pediatric palliative and hospice care will be different; however, many of the implications that arise from working in this population may ring true.

Burnout is the result of stressors due to the work (healthcare) environment (Rensenbrink, 2011). This may be caused by an incongruity in corporate values or unmanageable and/or difficult caseloads. Generally speaking, individuals with burnout may experience greater feelings of cynicism, ineffectiveness in their work and a lack of accomplishment.

Other symptoms may include:

- Poor judgment in clinical decisions
- Over identification and over involvement with patients and families
- Boundary and ethical violations
- Interpersonal conflicts, especially with fellow staff
- Addictive behaviors
- Gastrointestinal disturbances and headaches
- A questioning of one’s core spiritual or religious values

Compassion Fatigue, or secondary traumatization involves the distress directly correlated to patient care and the relationships that develop among the (therapist), patients and families.

Interestingly, the symptomology associated compassion fatigue, mirrors that of Post-Traumatic Stress Disorder (PTSD).

Symptoms may include:

- Greater risk of countertransference
- Irritability and hyper vigilance
- Increased difficulty concentrating
- Instances where the (therapist) re-experiences memories and/or intrusive thoughts
- A conscious or unconscious avoidance of similar types of experiences
- Sleep disturbances, commonly associated with nightmares
- A withdrawal from social situations

Disenfranchised Grief has three primary causes: (a) the relationship is not recognized, (b) the loss is not recognized, (c) the griever is not recognized (Rensenbrink, 2011). These added components to grief intuitively exacerbate the grieving process. “The concept of disenfranchised grief recognizes that society has a set of norms –in effect, “grieving rules”- that attempt to specify who, when, where, how and how long and for whom people should grieve” (Doka, 2002, p. 4).

Examples of disenfranchised grief may include:

- A man grieving the death of his ex-wife
- An adult with developmental disabilities being excluding from funeral rituals
- A healthcare professional losing a patient in hospice/palliative care

Among hospice caregivers, there appears to be an overarching theme of control. One may wish to control one's emotions by either disassociating from the emotional and spiritual needs of their patients, or avoiding thoughts and opinions about the death process. In terms of the "grieving rules", the general rule in the medical profession seems to be that healthcare professionals do not grieve the death of their patients. This has the potential to not only limit the professional's capacity for personal intimacy and emotional intelligence, but creates a sense of distance between coworkers and healthcare disciplines. This distance and lack of capacity for intimacy may in turn, affect the care of the patient and family.

Compassion Satisfaction, within this context, refers to the positive aspects that one experiences by being involved in a patient's care. "You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society" (HudnallStamm, 2012, p. 2). The ability to gain satisfaction from one's role in a patient's care and in an interdisciplinary team is vital for effective and long-term practice.

The Importance of Professional Self-Care

A moment of self-compassion can change your entire day. A string of such moments can change the course of your entire life ~Christopher Germer

What is Professional Self-Care?

The greatest risk factor for music therapists in this setting is the very nature of human service work and the emotional expectations instilled by others and one's self. In order to mitigate stressors accompanied with this type of work, clinicians benefit from regular practice of professional self-care. Professional self-care is defined as "the utilization of skills and strategies to maintain their own personal, familial, emotional and spiritual needs while attending to the needs and demands of their clients" (Newell & Nelson-Gardell, 2014, p. 431). Each music therapist may benefit from different types of self-care skills and strategies depending on a number of different factors, including individual personality traits and specific stressors experienced. Continuous reflection and creativity into one's self-care practice allows for a healthy and sustaining lifestyle both in and out of the work setting.

Personal Responsibility

Understanding the benefit and impact of regular self-care is critical for personal satisfaction and a sense of effectiveness in one's role as a music therapist. When one experiences stressors in the workplace, it is not uncommon to deny the need for moments of self-care or self-compassion. In fact, these are the moments when it is most crucial to engage in such practices. As clinicians, we have a personal and professional responsibility to take care of ourselves in order to take care of others. Compassion fatigue and/or burnout do not occur overnight. In the same regard, instilling new, healthy practices takes some time and effort. Making yourself a

priority and treating yourself with the same kindness that you would your patients has the power to support long-term and effective change.

Organizational Responsibility

Organizations, too, have a vested interest and responsibility to support their employees, especially when the work is so demanding and emotionally charged. The health-care environment remains a competitive market. Employees who feel supported and satisfied in their work are more likely to be highly engaged and effective in their role. An organization's ability to deliver a "high-quality patient experience" has direct correlations to funding and widespread reputation. "In fact, with a potential 2% loss in reimbursements for hospitals that cannot meet specific patient satisfaction and quality of care outcomes, the link from employee actions to patient experience to financial results could not be more direct" (Sherwood, 2013, para. 1).

Additionally, healthcare communities with high levels of employee satisfaction are able to retain and recruit more educated and highly skilled individuals. An organization's ability to recruit these types of employees in turn has a direct on the level and quality of care delivered to patients and families. The system thrives on the idea that "no matter how modern, sophisticated, or efficient staffing programs are, if the individuals who are executing the care are not qualified, engaged, and able to offer the caring necessary for healing, the whole system can unravel quickly" (Douglas, 2010, p. 415).

Assessing the Situation

When physical or emotional exhaustion is present, waiting for someone else to address it is not the answer. ~Kathy Douglas

Compassion fatigue and burnout fluctuate and may be difficult to identify in the moment. Waiting until signs or symptoms have become unmanageable or have dissipated may further exacerbate feelings of isolation. Understanding compassion fatigue and burnout, as well as how they affect you personally and professionally, can be essential in sustaining a long-term and meaningful practice.

The Professional Quality of Life Scale (ProQOL) is a tool that was developed to measure a helper's degree of compassion satisfaction, compassion fatigue and burnout. In broad terms, professional quality of life refers to "the quality one feels in relation to their work as a helper" (HudnallStamm, 2009). Utilizing this tool may bring to light the degree or severity that the music therapist is experiencing the effects of being in the helping profession. This assessment can be taken every thirty days as scores may vary in relation to one's current workload or stressors in the work environment. The authors give permission for use. Consent can be found at www.proqol.org/ProQol_Test.html.

Professional Quality of Life Scale (PROQOL)

Throughout this assessment, select the number that honestly reflects how frequently you experienced these things in the *last thirty days*.

1 = Never	2= Rarely	3= Sometimes	4= Often	5= Very Often
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- ___ 1. I am happy.
- ___ 2. I am preoccupied with more than one person I help.
- ___ 3. I get satisfaction from being able to help people.
- ___ 4. I feel connected to others.
- ___ 5. I jump or am startled by unexpected sounds.
- ___ 6. I feel invigorated after working with those I help.
- ___ 7. I find it difficult to separate my personal life from my life as a helper.
- ___ 8. I am not as productive at work because I am losing sleep over traumatic experience of a person I help.
- ___ 9. I think that I might have been affected by the traumatic stress of those I help.
- ___ 10. I feel trapped by my job as a helper.
- ___ 11. Because of my helping, I have felt “on edge” about various things
- ___ 12. I like my work as a helper.
- ___ 13. I feel depressed because of the traumatic experiences of the people I help.
- ___ 14. I feel as though I am experiencing the trauma of someone I helped.
- ___ 15. I have beliefs that sustain me.
- ___ 16. I am pleased with how I am able to keep up with helping techniques and protocols.
- ___ 17. I am the person I always wanted to be.
- ___ 18. My work makes me feel satisfied.
- ___ 19. I feel worn out because of my work as a helper.
- ___ 20. I have happy thoughts and feelings about those I help and how I could help them.
- ___ 21. I feel overwhelmed because my caseload seems endless.
- ___ 22. I believe I can make a difference through my work.
- ___ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I help.
- ___ 24. I am proud of what I can do to help.
- ___ 25. As a result of my helping, I have intrusive, frightening thoughts.
- ___ 26. I feel “bogged down” by the system.
- ___ 27. I have thoughts that I am a “success” as a helper.
- ___ 28. I can’t recall important part of my work with trauma victims.
- ___ 29. I am a very caring person.
- ___ 30. I am happy that I chose to do this work.

What Is My Score and What Does It Mean?

In this section, you will score your test so you understand the interpretation for you. To find your score on **each section**, total the questions listed on the left and then find your score in the table on the right of the section.

Compassion Satisfaction Scale

Copy your rating on each of these questions on to this table and add them up. When you have added them up, you can find your score on the table to the right.	3. _____	The Sum of My Compassion Satisfaction Questions is	So My Score Equals	And My Compassion Satisfaction Level Is...
	6. _____			
	12. _____			
	16. _____			
	18. _____			
	20. _____	22 or Less	43 or Less	Low
	24. _____	Between 23 and 41	Around 50	Average
	27. _____			
	30. _____	42 or More	57 or More	High
	Total: _____			

Burnout Scale

On the burnout scale, you will need to take an extra step. Starred items are "reverse scored." If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way through they can tell us more about their negative form. For example, question 1. "I am happy" tells us more about the effects of helping when you are <i>not</i> happy so you reverse the score.	*1. ____ = ____	The Sum of My Compassion Satisfaction Questions is	So My Score Equals	And My Burnout Level Is...
	*4. ____ = ____			
	8. ____			
	10. ____			
	*15. ____ = ____	22 or Less	43 or Less	Low
	*17. ____ = ____	Between 23 and 41	Around 50	Average
	19. ____			
	21. ____	42 or More	57 or More	High
	26. ____			
	*29. ____ = ____			
	Total: _____			

Secondary Traumatic Stress Scale

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.	2. _____	The Sum of My Compassion Satisfaction Questions is	So My Score Equals	And My Secondary Traumatic Stress Level Is...
	5. _____			
	7. _____			
	9. _____			
	11. _____	22 or Less	43 or Less	Low
	13. _____	Between 23 and 41	Around 50	Average
	14. _____			
	23. _____	42 or More	57 or More	High
	25. _____			
	28. _____			
	Total: _____			

Your Scores on the PROQOL: Profession Quality of Life Screening

Based on your responses, place your personal scores below. If you have any concerns, you should discuss them with a physical or mental health care professional.

Compassion Satisfaction _____

The average score is 50 (SD 10; alpha scale reliability .88). About 25% of people score higher than 57 and about 25% of people score below 43. If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 40, you may either find problems with your job, or there may be some other reason – for example, you might derive your satisfaction from activities other than your job.

Burnout _____

The average score on this scale is 50 (SD 10; alpha scale reliability .75). About 25% of people score above 57 and about 25% of people score below 43. If your score is below 43, this probably reflects positive feelings about your ability to be effective in your work. If you score about 57, you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood; perhaps you were have a “bad day” or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern.

Secondary Traumatic Stress _____

The average score on this scale is 50 (SD 10; alpha scale reliability .81). About 25% of the people score below 43 and about 25% of people score about 57. If your score is about 57, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional.

Musical Check-Ins

As music therapists, we often have deep, personal connections to music. “We often describe our work as a calling, a way of life, a world view” (Hesser, 2001, p. 53). Through this type of understanding and connection, we view music as a modality that supports self-awareness and a sense of overall wellness. Incorporating music into our regular “check-ins” may not only provide us with a greater sense of self-awareness but also provide us a deeper understanding of music as a healing modality and a professional discipline.

Music Improvisation

Music improvisation is the process wherein the player extemporaneously creates music through singing and/or playing instruments. Music improvisations can be classified as either referential or non-referential. **Referential improvisation** “is one that is created in reference to something other than the music itself for example, an image, title, story, feeling or a work of art” (Gardstrom, 2007, p. 16). Music therapists may find using a referent as a positive framework for exploring thoughts or feelings. Therefore, **non-referential improvisations** are works created extemporaneously without any external ideas or concepts. The improvisation has no direction other than music created.

Improvising musically has the potential to support a greater sense of self-awareness. Through the music, one may become cognizant of major themes of concern or frustration. Nordoff-Robbins music therapists believe that the “work is seen as an outer manifestation of a client’s inner life” (Aigen et al., 2008, p. 69). In this right, we can understand and work through difficult thoughts or feelings, using music as our support and/or guide.

Potential Directions for Improvisation

- 1.) Focus on your day at work
- 2.) Reflect on your role as a music therapist
- 3.) Improvise around the death of a patient

- 4.) Consider your current emotional state and improvise around your feelings
- 5.) Examine elements of work that bring you joy or fulfillment - reflect these in your playing
- 6.) Improvise without a referent, noticing any thoughts or feelings that arise through the process.

Tuning Into Your Musical Listening

Pay attention to the music to which you feel drawn to listen to. An individual may choose particular genres of artists during a specific time for a variety of reasons. These include (1) creating a sense of personal space, (2) filling time while completing mundane tasks, (3) social purposes, (4) aesthetic pleasure, or (5) regulating moods (Garrido& Schubert, 2011, p. 220). The music that we listen to is often affected by our present circumstances or emotional state. Furthermore, songs may pop into your head as you go about your day. These too, may reflect your thoughts and feelings. For one week, try to keep record of the songs that arise while you are going about your day.

Date	Song Title	Artist	Thoughts When Song Arose	Any Associations with the Song

Following the completion of your log, reflect on any songs that are currently resurfacing. Note any recurring themes or thought patterns during the process. Using the log periodically may provide opportunities for greater insight or awareness.

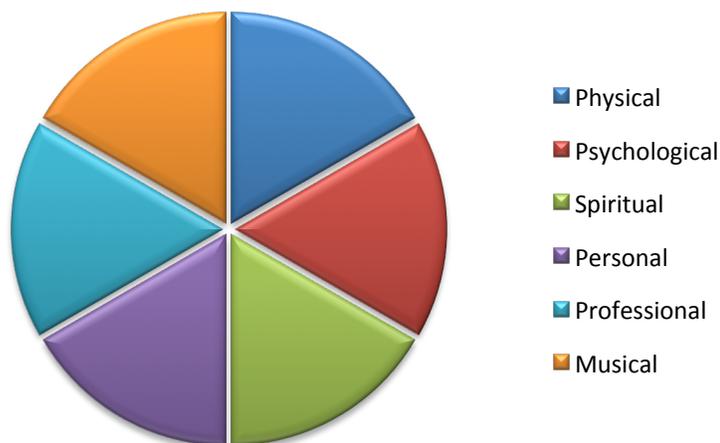
Making Meaningful Change in One's Self

I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival. ~ AudreLonde

It Begins with You

While external factors can contribute to one's risk of compassion fatigue or burnout, it is ultimately one's responsibility to make self-care a priority. Without the ability to care for one's self, it is impossible to care for others. Furthermore, becoming self-aware and recognizing your personal needs will allow you to cultivate a deep sense of self-compassion that will support the concept of overall wellness. While each therapist's needs will be different, attending to various domains of health will best support a well-balanced life-style. These facets are broken into physical, psychological, emotional, spiritual, personal, professional and musical pieces.

Music Therapist's Wheel of Wellness



Adapted from (Myers & Sweeney, 2004)

Building a self-care practice that takes into account each of these regions facilitates the development of positive coping skills. Self-compassion, modeled through self-care techniques, helps us as clinicians, develop resiliency. Finding resiliency in the face of suffering and adversity

is a model of behavior that we can pass on to our colleagues, patients and families. Consider resiliency like a muscle, only growing stronger when moved and developed through consistent work and attention.

Below, each domain is elaborated upon in greater detail. Warning signs will be discussed and suggestions will be made to address areas that appear to be deficient. Exercises and interventions provided are not intended to be exhaustive but rather provide a “jumping off point” for continued exploration. While you may feel more drawn to particular domains of health, challenge yourself to instill at least one new technique or exercise from each area. After reading the following sections, use the prompts below to motivate and guide your personalized self-care practice.

- 1.) What signs and symptoms stand out most for me?
- 2.) What signs and symptoms do I bring home with me most often?
- 3.) What signs and symptoms do I experience at work?
- 4.) What do I have to lose if I don't deal with the effects of burnout/compassion fatigue?
- 5.) What do I stand to gain if I move towards more improved self-care?
- 6.) Who will be the biggest supporters of my self-care?

(Mathieu, 2012, p. 60)

The Physical Domain

Warning Signs:

- Physical exhaustion
- Insomnia
- Headaches or migraines
- Increased susceptibility to illness
- Somatization of illnesses

Sleep

When experiencing a great amount of stress at work, this often carries negative implications of our sleeping habits. “We go to bed too late (often while watching television or on the Internet), sleep poorly, worrying about work and other life matters, and keep ourselves going by drinking coffee throughout the day” (Mathieu, 2012, p. 106). A lack of sleep can have an impact on your brain’s functions, leading to forgetfulness, impaired judgment, a quicker temper and may lead to depression (Fisher, 2014).

Are you getting enough sleep each night? In order to properly assess your sleep debt, try lying in a darkened room on the floor or a couch for 10-15 minutes. If you are able to fall asleep, this is an indicator of being sleep deprived. Being cognizant of good sleep hygiene, establishing a nightly routine and limiting food, electronics and stimulants right before sleep has a positive correlation to an increased amount and quality of sleep,

Exercise

When caregivers are feeling overburdened or bogged down, exercise tends to be one of the first components of self-care we forget. However physical movement and exercise can make a significant impact on our overall wellness. Regular exercise releases neurotransmitters, dopamine and serotonin. Dopamine releases “feel good hormones,” playing a part in controlling

the brain's pleasure center. Serotonin aids in feelings of peacefulness. Low serotonin levels have been linked to clinical depression.

Slowly increasing your physical activity over time is a wonderful way of supporting your own self-care practice. These can be small changes like taking the stairs instead of the elevator or parking farther away from the hospital to increase your opportunities for walking. Creating physical goals can be helpful for continued motivation, such as running a 5K or attending a new type of exercise class. Enlist the help of a family member or friend to add opportunities for positive social interactions and accountability.

Eating Well

The saying, “you are what you eat” rings true. The foods you choose to put into your body can make all the difference. Eating a diet that is rich in fruits and vegetables is a part of an overall healthy diet that supports health and wellness. It allows the individual to maintain a healthy weight, often leading to an improved self-image. A healthy diet supports an increased sense of energy and brain functioning, allowing the clinician to be more present in their personal and professional roles.

Like exercise, small changes to your diet can make a long-lasting impact on your body and mind. Try choosing and maintaining one new, healthy habit each week. These can be simple modifications like cutting out sugary drinks or bringing healthy snacks as a better alternative. Building upon these goals will support long-term change.

The Psychological Domain

Warning Signs:

- Emotional exhaustion
- Anger and irritability
- Reduced ability to feel sympathy and empathy
- Hypersensitivity to emotionally charged stimuli

Positive Affirmations

“Unfortunately, as therapists, we learn that dysfunctional ways of perceiving ourselves and the world are common and often left unchallenged. Such inattention is psychologically dangerous – especially if you are a clinician” (Wicks, 2008, p. 145). Finding or creating positive affirmations that confirm your positive attributes as a music therapist not only bolster your sense of confidence but aid in the effectiveness of your clinical work and communication with others.

A wonderful way to start creating your own affirmations is by noticing the negative self-talk you engage in throughout the day. If there is a specific attribute or phrase you notice, use this as inspiration. If your negative self-talk tells you, “I am not going to be able to get through this day”, create its opposite phrase, such as “Today will provide me with what I need”. Other potential affirmations include...

- I am a talented music therapist
- I am worthy of peace
- I am in control of my life
- I am able to solve problems creatively
- I accept myself unconditionally, right now

Practice Asking for Help

As a member of a caring profession, we are often in tune with other’s needs. Recognizing our own needs and asking for help can seem much more difficult. For whatever reason, we don’t want to burden our coworkers, we may be viewed as weak, or feel that should be accomplish it

on our own. However, we need to learn how to be comfortable with the uncomfortable, seeking out support when needed. This provides us with the reminder that we are not alone in the workplace, fostering a deeper sense of community among team members. By asking for help, you are trusting in others, allowing such trust to be mutually strengthened. We are all perfectly imperfect and are worthy of support in our work as end-of-life care providers.

Saying Goodbye

Music therapists are not always present during the active, dying process. In these cases, saying goodbye or receiving some type of closure may not always be possible. Developing some type of ritual, like writing a letter to that patient, may be helpful in your own processing. Engaging in this type of reflection is for your own personal use and does not need to be shared with anyone other than yourself.

Dear _____

I remember a time we _____

You taught me _____

I feel _____

I hope _____

Thank you for _____

Adapted from Grief stages and goodbye letter. (2014). Retrieved from <http://www.lorinda-charactereducation.com/p/grief-10-stages-of-grief-1.html>

The Spiritual Domain

Warning Signs:

- Loss of hope
- Disruption of spiritual beliefs
- Existential crises

Mindful Living

Living mindfully comes from four major components: authenticity, intentionality, openness and grace. *Authenticity* refers to your ability to live the “truths” in your heart rather than unhealthy coping skills. It requires self-awareness and courage to live in a way that is genuine to one’s personality, spirit or character. *Openness* is the ability to embrace life’s moments, remaining “open” and accepting to what may come. *Intentionality* allows individuals to be present and responsive to their surroundings. We refrain from going on autopilot or tuning out the world around us. Finally, *grace* is the attitude that we adopt, accepting that which is not perfect. Through a graceful mindset, we are better able to let go of expectations and cultivate a deeper sense of empathy.

Spiritual Space

A sense of place or a personal oasis may be strengthened by a “spiritual home.” For some, this may mean attending a place of worship such as a church, temple or mosque. Others may find spirituality in an internal place, composed of a system of moral codes and existential beliefs. Utilizing these interventions and those below can help support the identification or development of one’s “spiritual place”.

A Sense of Place

Most full-time clinicians spend a great deal of time in the hospital setting. Forged by a quick pace, fast deadlines and often-unmanageable caseloads, the environment itself can be a tumultuous space to stay grounded. Remaining present and observant within the environment is a cornerstone to effective practice. How does one create an environment that is conducive not only to the needs of the patient but also to the needs of themselves and their colleagues? Is it possible to create an “oasis” amongst suffering?

A Place of Healing

Too often in the medical environment, we become primarily disease-focused. Often staff have difficulty when asked “to apply the art of medicine to individual patient’s unique illness, with particular attention to the nuances of social circumstance and culture” (Green, Carrillo, & Betancourt, 2002, p. 141). Physical symptomology can easily become the only focus of care. We can lose sight of the psychosocial needs of our patients and families when pain or disease is particularly aggressive. Keep the concept of holistic healing in the forefront of your mind. Each time you meet with a patient or family ask yourself, “What is my objective with meeting with this person? How can music therapy support them in creating person-centered care?”

A Community, A Shared Identity

The theme of mutual support is founded on the principle of a common or shared identity. It is my belief that members of the interdisciplinary team enter their respective fields because they wish to help others. More often than not, care providers believe that quality of life is an important aspect of their team’s overall mission. Coming together to identify and reiterate common themes or mission statements supports the concept of a shared community or identity. With this common purpose in mind, a bond is created that furthers the overall concept of care.

Gaining Perspective

One of the more challenging aspects of working in end-of-life care is the frequency of patient deaths. It becomes more commonplace to see and hear the aspects that often accompany end-of-life work. Encountering illnesses such as cancer and cystic fibrosis may feel like “the new normal” in everyday life. It is important to find ways to gain perspective in order to remember that the world is also full of healthy individuals. One way to encourage a realistic perspective is being around well children, spending time with your own or perhaps babysitting others.

Natural Environment

The cold, clinical atmosphere that is typically associated the medical environment can become a contributing factor in burnout. The typical “hospital smell,” is marked with a distinct odor caused by disinfectants. This type of smell can create olfactory memories, potentially triggering feelings of stress or anxiety. The fluctuating temperature changes also may cause feelings of discomfort. Making time to be out in nature is a significant aspect to supporting one’s health. Even if only for a few moments each day, stepping outside the hospital walls and getting some fresh air can help refocus the mind.

Spiritual Place

A sense of place or a personal oasis may be strengthened by a “spiritual home.” For some, this may mean attending a place of worship such as a church, a temple or mosque. Others may find spirituality in an internal place, composed of a system of moral codes and existential beliefs. Utilizing these interventions can help encourage the identification or development of one’s “spiritual place”.

The Personal Domain

Warning Signs:

- Negative self-image
- Avoiding friends and family
- Problems with intimacy
- Failure to nurture and develop personal aspects of life

Healthy Relationships

Having healthy relationships outside of the workplace provides support and encourages a work/life balance. These types of relationships, with friends or family, should be based in a sense of mutual respect. Through these connections, there is trust, honesty, and cooperation between one another. Beyond the hospital walls, healthy relationships can provide a safe space to process difficult emotions. These spaces also allow us an outlet to have fun and cultivate personal hobbies and interests.

Personal Hobbies

While music therapy is an incredible profession, it cannot be one's whole identity. Personal hobbies help shape an individual and encourage a healthy work life balance. They remind us and enforce the idea that it is important to take breaks. Use the worksheet below to try new types of activities that interest you and bring you joy, unrelated to your occupation. After exploring

The Professional Domain

Warning Signs:

- Difficulty separating personal and professional lives
- Diminished sense of enjoyment in career
- Providing compromised care for patients
- Exaggerated sense of responsibility
- Avoiding patients

Transitioning from Home To Work

It is not uncommon to have two identities. There is you, the music therapist and there is you, the friend, musician, husband, wife, sister, uncle, etc. As you prepare to drive to work or are heading home for the day create a ritual that helps quiet the mind and signifies such a shift. For instance, on your drive, find a marker that represents a halfway point. Leave your worries and difficult cases there for the day. When you drive past this point the next morning, you can pick it up and have time to process these before arriving at work. Others may find it helpful to change their clothes or shower before engaging with others or personal activities.

Taking Vacation

“About 42 percent of Americans said that they did not take a single vacation day last year” (Picchi, 2015, para. 1). Missing a year’s worth of vacation has been associated with a greater risk of heart disease and a loss in job satisfaction (Picchi, 2015). Regardless of reasoning to delay time off, taking vacations can positively impact your personal and professional well-being. Furthermore, taking “work-free” vacations, without checking emails or “catching up” on administrative responsibilities, encourages a work/life balance. Work-free vacations also allow you to increase your focus and creativity when returning back to your place of work.

Professional Development

Many music therapists are the only one at their facility. This isolation can be disheartening and lead to a loss of professional identity. Attending and/or participating in conference, classes and seminars provide a venue for new ideas, support and a reinstallation of professional satisfaction. A number of opportunities for professional development are available at both the regional and national levels. Contact the American Music Therapy Association (AMTA) or your state's association for upcoming opportunities. Getting involved through attendance or contribution strengthens relationships with other music therapists and encourages growth as a clinician.

Clinical Supervision

Seeking out clinical supervision can be extremely beneficial to a music therapist's practice. It involves a professional relationship where the supervisee is able to process the complexities of the work and aid in continued professional development. "With the advent of licensure and an increased need for accountability along with a desire to deepen understanding of music therapy and the various approaches which make up this complex field, supervision has begun to be recognized as a necessary and important part of the process of becoming a practicing music therapist" (Rafieyan, 2009, para. 3). While we receive supervision as students and interns, the opportunities following certification may seem less available to us. As technology has continued to advance, the ability to receive quality supervision has increased regardless of geographical location. Discuss clinical supervision with your employer as many facilities may help reimburse for these services.

The Musical Domain

Warning Signs:

- Avoidance of songs or instruments
- A clinification of music-making
- A loss interest or investment in personal music-making

Why Is Musical Self Care Important?

Individuals who have chosen the music therapy profession often see it as much more than a job. Rather, they are honoring a life's calling to be in music and to help others do the same. Too often, these original feelings become muddled under their daily work. Whether we lose sight due to corporate strain or the high acuity of our patients, music becomes a means to an end. In this way, we lose the joy of such a creative and meaningful profession. "Music therapists need to allow themselves to be truly moved and changed by the healing power and beauty of music. We need to spend time making music, listening to music, and exploring the uses of sound and music for our own personal growth and transformation" (Hesser, 2001, p. 53). When we invest in our own musical needs, we are better able to support our patients and families in the same context.

Creating Playlists

Creating playlists can create a window and a means of deeper exploration of one's connection to music. Start by making a playlist of all your favorite songs. Upon completion, reflect on what you appreciate about these selections. What about these songs do you value most? Keep a journal to help you explore this further. Further prompts for playlist creation could include selections that...

- Remind you of your childhood or adolescence
- Resonate with your role and/or decisions to be a music therapist
- Help you relax or find a sense of peace
- Reflect your current emotional state

Tend To Your Musical Self

Many music therapists entered the profession due to their own experiences with music. For some, this may have been participating in school activities such as choir or marching band. Others have perhaps had professional experiences in the music industry. Regardless of what your personal music making was, it is common that these activities may wane once entering the field. After coming home from a day of playing music, it may at times seem like another obligation to engage in personal music-making. However, it is through our own experiences that we are truly reminded of the healing qualities of music. Write your own ideas for musical involvement. Spend time thinking about each one imagining participating in that activity. Which ideas resonate most deeply?

- Joining a choir
- Writing a song
- Learning a new instrument
- Attending a concert

Seeking Out Personal Music Therapy

Another wonderful thing that music therapists can do is to seek out their own music therapy. “The idea of therapy for the personal growth and development of the music therapist is slowly becoming more accepted. [...] All people, including music therapists, can benefit from music therapy at some point in our lives” (Hesser, 2001, p. 55). Having this type of experience allows a unique window for personal growth and increased self-awareness. One is able to explore the benefits of music therapy from a personal perspective, perhaps also strengthening their professional identity.

Bringing Together the Healthcare Community

Coming together is a beginning. Keeping together is a progress. Working together is success.

~Henry Ford

Dissonance occurs when individuals lose their connection with others in the workplace. When clinicians feel a lack of respect or pressure to display and/or inhibit emotional responses around colleagues, communication can be obstructed. Unfortunately, the medical environment is not always viewed as a compassionate setting for its healthcare workers. It is not uncommon for many clinicians to take on larger caseloads and with fewer resources. In particular, “the traumatization of young professionals in their early practice, widespread bullying in healthcare and unresolved emotional responses to human suffering and loss, lead to distancing and isolation rather than trusting relationships” (Rensenbrink, 2011, p. 45).

Stress is molded not only by one’s individual psychology but also a number of contributing, social factors. Mutual support, trusting relationships, and open disclosure are vital for creating effective, interdisciplinary cohesion and an overall healthy, work environment. Playing a part in this instillation of a mutually supportive practice creates a safe space for processing difficult situations and emotions. As a result, deeper, more valuable relationships may be experienced amongst colleagues.

Open Disclosure, Trusting Relationships and Mutual Support

These three components meld into one another, providing the framework for positive work relationships. “Close communication was by far the most frequently mentioned criterion for cooperation” (Rensenbrink, 2011, p. 11). This open communication provides a safe space for colleagues to be open and honest with the stressors that accompany their job responsibilities and population’s demographics. Disclosure with colleagues may be either informal or formal. Examples of informal processing may include discussing a difficult patient experience while in

one's office or while awaiting the start of an interdisciplinary meeting. More formal means of processing include agenda items like patient remembrance or more immediate debriefings following the death of a patient. A culture that supports frequent and open communication fosters more authentic and trustworthy relationships.

Trusting one's co-workers is one of the most important aspects of a healthy working relationship. This type of assurance and confidence is fostered over time, supported through open and authentic dialogue. Trusting one another allows for a more collaborative work environment, better supporting the needs of patients and families as well as employees. For instance, professionals in this type of setting often develop deep rapport with their patients. As a result, they may cultivate feelings that *only they* can provide adequate care for the individual. Being able to recognize the strengths and skills of others, developing that trust, takes away some of the pressure of providing all emotional and/or psychosocial support. We work in interdisciplinary teams to better delegate the difficult workload.

Together, open communication and trustworthy relationships between coworkers promote an idea of mutual support. Mutual support may be providing a safe space for colleagues to discuss thoughts and feelings surrounding the concept of end-of-life care. Individuals may feel more comfortable processing and recognizing one's own suffering in the context of their role as music therapist. Furthermore, we as professionals may feel more open to the idea of sharing their needs when experiencing difficulties. Departments may choose to redistribute the workload at times to better accommodate the needs of their clinicians. For instance, following the death of a patient, a coworker may follow-up with their next appointment in order to give that individual a few moments to process. It is our responsibility, especially when working in this population, to both advance the concept of mutual support as well as be open to accepting it when needed.

The Investigation, Reimagining and Installation of Boundaries

Boundaries are part of self-care. They are healthy, normal and necessary ~ Doreen Virtue

Healthy boundaries are considered the cornerstone to professional practice. Especially when working with such a vulnerable population, understanding and instilling these boundaries will prevent ethical dilemmas or abuses and allows professionals to take better care of themselves. However, each therapeutic relationship develops differently and can look different depending on the individuals involved. In some instances, boundary violations occur subtly where the clinician is unaware until reflecting back at a later time.

Working with ill children and adolescents can increase the risk that boundaries may blur or become unclear. The emotional complexities that accompany caring for children are numerous and multifaceted in nature. Clinicians may find themselves attempting to exhibit more maternal or paternal behaviors. For instance, “when parents are either physically or emotionally unavailable to their children, the struggle intensifies as the health care provider tries to fill the gaps of care and advocacy. These issues add to the complexity of relationships in pediatric health care settings” (Rollins, 2005, p. 494). So what is the balance between providing supportive care and delineating healthy boundaries?

“Biomedical Boundaries”

In Western society, we practice medicine under a Biomedical approach. This has been considered the primary model physicians use in order to diagnose disease or illnesses. The Biomedical model excludes all emotional and psychosocial factors, solely relying on physical processes to make a determination. For a great deal of time, this type of practice in the distribution of cares was highly valued. Within the Biomedical model of care, clinicians exhibit an emotional distancing or detachment from patients. Rather than viewing patients as a whole person, it was considered more appropriate to see them as a biologic body. This emotional

detachment was viewed as a protecting force from compassion fatigue and potential boundary violations. However, others pose the question: “Could it be that emotional distancing as the primary strategy of professional self-protection is, in fact, actually exacerbating the very problem it is intended to help?” (Rensenbrink, 2011, p. 51).

Being Too Emotionally Detached

The romanticism of emotional detachment in the medical environment has led to unattainable standards for health-care professionals to achieve. Learning to separate the person from their physiological body can result in a loss of the ability to empathize with others, in and out of the professional work setting. This intuition and ability to comprehend one’s feelings can affect the music therapist’s ability to promote positive change or wellness in the patient. As the musical space created between patients and therapists can be considered uniquely intimate, it is important that the therapist is able to remain present and emotionally available in order to deliver meaningful care.

Being Too Emotionally Available

On the other side of the coin, being too emotionally vulnerable can lead to great risks for both the therapist and the patient. Going above and beyond one’s professional duties and responsibilities often leads to great ethical dilemmas. Patients and families receiving greater care or preferential treatment may come to feel uneasy with the added attention or connection. Other patients and families may begin expect an unrealistic level or amount of care throughout their hospice/palliative care journey. As families also connect with one another while inpatient, they may witness a contrast in levels of time and care.

Furthermore, being too emotionally available often leads to great feelings of pressure and unrealistic sense of personal responsibility. We may come to feel that only we are able to provide

adequate care to that patient or family. This can lead to a lack of trust in our co-workers and this absence of trust and communication can lead to great feelings of isolation and a breakdown in the hospice/palliative care team. Together, these components can play a part in the onset of burnout and/or compassion fatigue.

Reflecting on Boundaries

When questioning one's boundaries with a patient, it is important to take a moment to reflect on the nature and development of the relationship. Jameson (1993) suggests using the following questions when considering potential violations of professional integrity.

- What is it possible for me to do?
- What is the extent of my personal responsibility?
- When others are not meeting their responsibilities, what is the extent of my responsibility to compensate for their omissions?
- What personal risks are [music therapists] obligated to take for patients? For their profession? For themselves?

Furthermore, Willis-Brandon (1990) identifies a number of thoughts or actions that may alert the clinician of potential boundary violations.

- Exaggerated feelings of shame, guilt, or inadequacy
- Seeing oneself as a victim
- An exaggerated sense of responsibility for things beyond one's control
- Setting unrealistic expectation of oneself or others
- Inability to tolerate differences in approach or human error
- Avoiding conflict or confrontation
- Giving help when it is not needed or requested
- Putting the needs of others above personal needs

If experiencing these types of feelings or you find yourself engaging in similar behaviors, clinical supervision can be an extremely helpful tool. Supervision as a self-care practice is discussed in greater detail on page 50.

Exquisite Empathy

Exquisite empathy can provide a healthy balance and more person-centered, holistic approach to attending to patients. It is defined as empathic engagement –“discerning, highly present, sensitively attuned, well-boundaried and heartfelt” (Rensenbrink, 2011, p. 52). It is seen as an authenticity and in-the-moment presence that allows one to provide quality patient and family-centered care. This provides an atmosphere where patients and families are able to process their difficulties of treatment and feel more comfortable expressing themselves through music. The components of integrating exquisite empathy into one’s practice include self-knowledge, self-empathy, mindfulness, and contemplative awareness.

1. Self-Knowledge: Self-knowledge is the groundwork for gaining professional self-awareness. It is the understanding of what makes us the clinicians we are: our family history, cultural background, relationship to music, etc. Self-knowledge also involves our understanding of our emotional triggers and reactivity.

2. Self-Empathy: Self-empathy refers to one’s ability to recognize the feelings in their heart. It evolves beyond the act of engaging in self-care, instead suggesting that we examine how critical we are of ourselves. When exhibiting a sense of self-empathy, we are aware of our imperfections and shortcomings but accept them.

3. Mindfulness: Mindfulness, often tied to Eastern traditions, is the attention to one’s thoughts and feelings without judgment. The practice of mindfulness encourages individuals to be aware of the physical sensations that occur within the body. For

instance, noticing tightness in your chest could suggest feelings of anxiety. Noting these sensations, reserving judgment of one's self, supports the development of deeper self-knowledge and awareness.

4. *Contemplative Awareness:* Contemplative awareness pertains to the way we view ourselves in the larger scheme the world. It provides us with a conceptual framework for understanding our interconnectedness to others as we come in contact throughout our daily lives. Contemplative awareness has the potential to give greater meaning and a sense of purpose to our work.

Recognizing the Purpose and Impact of Music Therapy at End-of-Life

Music is the medicine of the breaking heart ~ Leigh Hunt

Music therapists choosing to work with children and adolescents with terminal illnesses do so because they believe that music can play an influential role in fostering a sense of wellness and quality of life. At times, it can be easy to lose this central mission through experiencing difficulties such as corporate politics, unmanageable caseloads, frequent patient deaths and lack of support in the work place. However, it is important not to lose sight of all that music therapy can do to support patients and families at this stage of care. Taking time to revisit the benefits of this modality has the potential to strengthen the music therapist's professional conviction, supporting a greater sense of meaning in the work.

Reduction of Pain and Anxiety

Pain is a serious concern for all health care professionals on the patient's care team. It is an important piece of almost any professional's assessment. "If a patient is in too much pain, there is usually not enough desire or energy to devote to other needs" (Hanson-Abromeit & Colwell, 2008, p. 164). Patients who experience chronic pain are less likely to tolerate medical procedures or be involved in their own daily cares. Chronic pain issues may also create a rift in the relationship between patients and their families with the medical team (Hanson-Abromeit & Colwell, 2008).

Furthermore, pain and anxiety often create a vicious cycle. As the medical environment is new and unfamiliar, this may cause feelings of apprehension. As an individual's anxiety increases, muscles often tense and breathing becomes more rapid. The lack of oxygen and tension of the individual's muscles creates the probability for a greater perception of pain (Yinger, Walworth, & Gooding, 2014).

Music has been shown to be a cost-effective treatment modality to provide a way to refocus one's attention from pain and anxiety. Depending on the type of pain (e.g. chronic, acute, or procedural) it is the music therapist's role to promote comfort, relaxation and the development of positive coping skills. Through music, patients are encouraged to explore new techniques to manage their pain; perhaps learning to rely on them without continuing to increase pain medication. This type of non-pharmacological pain management decreases the risk of opiate dependency over time (Bright, 2002).

Reintegration of Family

“The music therapist's ability to bring music and beauty to a difficult situation can be transformative for the family and the patient in their last moments” (Sluzewski, 2011, p. 54). Patients may also be at risk for decreased social support. Depending on the family's resources, the parents may not always be able to be present in their hospital. Parents who are able to stay with their child may feel helpless or unsure how to support the patient during procedures or medical treatments. If parents are torn on important medical decisions regarding a patient's treatment, this could potentially create a rift in the family unit. These arduous responsibilities, often combined with feelings of guilt, being unable to help their child avoid pain and suffering, can cause diminished communication within the family unit.

A child or adolescent diagnosed with a chronic or terminal illness may be experiencing a number of psychological and physiological changes. Parents and siblings may be unsure how to interact with the patient if the patient's capacity to engage has diminished. Patients may also be separated from their friends and outside support systems, depending on where they are being treated. This lack of social interaction may lead the child to withdrawal, a decrease in self-esteem and communication with others.

Through music, families can connect and relate to one another while providing the patient an opportunity to be successful, no matter their level of engagement. In this light, music therapy can strengthen relationships among family members and help them connect in a way that does not require words. In an interview, “three parents referred to music therapy as something for them and their child by either being able to enjoy the sessions together or to have a bit of a break while their child was engaged in music therapy” (Lindenfelser, Grocke, &McFerran, 2008, p. 338). Families may benefit from seeing their child have a positive experience in the midst of adversity, even as their child’s functioning continues to decline over time.

Locus of Control

“Even more than adults, children perceive much of their medical treatment as unpredictable and beyond their control” (Bradt, 2013, p. 22). Due to the erratic nature of the hospital environment, it is not uncommon for patients to experience an array of emotions due to the frequent incidences of loss of physical functioning and familiar environment, separation from loved ones and a lost sense of internal local of control. As pediatric patients often lack the proper expressive abilities to accurately describe their fears and an ever-changing concept of self, they can be the most susceptible and vulnerable to long-term psychological upset.

Numerable opportunities are available within the context of a music therapy session to make choices and take back a locus of control. Patients have the opportunities to make decisions regarding various music aspects including properties such as tempo, instrumentation, song content and level of engagement. By allowing for opportunities for control, patients may be more open to accepting medical cares and medication compliance. This flexibility also promotes the overall concept of family-centered care and strengthens the relationship between the patient, therapist and family.

Positive Relationships

Relationships that are developed through music therapy can also play an impactful role during hospitalization. Through these relationships, patients may feel more comfortable engaging in opportunities for emotional expression (Runningdeer, 2013; Maue-Johnson & Tanguay, 2006). Professional music therapy can promote quality of life through features such as (a) honoring a person's identity and self-worth, (b) providing the chance to engage in a meaningful relationship, (c) offering the opportunity to engage in a mentally stimulating activity, and (d) having something to look forward to (Bright, 2002).

Therapeutic Environment in End-of-Life Care

“A critical and often difficult period for families and loved ones is the time immediately before the patient's death” (Krout, 2003, p. 129). Music therapy has the ability to provide comfort to the patient's family if the patient is actively dying or has recently passed. Families may become more distressed as the patient begins to approach death, witnessing social, emotional, spiritual and physical changes in their loved one. As the patient enters the stage of active dying and death, symptomology intensifies.

Music therapy can develop a therapeutic environment for end-of-life care. Through music, patients may experience relaxation, management of pain and anxiety and a support of religious and spiritual beliefs. However, music has the ability to provide support and comfort during this difficult time. The acronym VINE was developed to reflect how the hospice team attempts to support families, Validating, Identifying, Normalizing, and Expressing feelings associated with anticipatory loss (Krout, 2003). Music can support this facilitation and stimulate discussion and life review in a non-threatening approach.

Leaving Legacies

Additionally, families may be concerned that they could forget the characteristics that made their child unique. Patients, particularly adolescents, may worry that once they have passed, that the world will forget about them. It is a search for meaning and connectedness, allowing a part of those who have passed to live on.

By creating recordings of patients in hospice and palliative care, patients and families can “create something that can preserve the humanity of a situation” (Cincinnati Children’s Hospital Medical Center, 2014). Following the death of that child, parents can maintain a sense of connection and assist in the grieving process. “The majority of parents stated that music therapy had contributed significant to the memory of their child and ‘gave them something to hang onto’ after their child had died” (Lindenfelser, Grocke, &McFerran, 2008, p. 339).

Our Common Goals as Music Therapists

“The future of music therapy within palliative care is promising due to the compassionate and creative people that persistently pioneer new ideas, initiatives, strategies, formulas, methods and research” (Schreck, 2014, p.37). Let us remember why we entered this profession and why we find our work meaningful. On the days where the work seems draining or difficult, take the time to step back and remember the benefits your patients and families are receiving from this type of care. Create a physical or mental list of moments where you really felt like you were making a difference. Come back to this when you need a boost.

Conclusion

You are the music while the music lasts ~ T.S. Eliot

Following the death of a patient, it is uncommon for me to have the opportunity to speak with families. However, recently I received a phone call from the mother of a former patient who had passed away months prior, asking to meet during her upcoming visit. Upon her arrival, I was flooded with memories of her time at the hospital, watching her walk up and down the inpatient hallways with her son. She walked with such a confidence and calmness, which suggested to me, a sense of home in the hospital. I suppose in a way, it did become her home for a while. After greetings and brief pleasantries, we, and a few other members of the treatment team, walked outside the hospital walls to release balloons in honor of her son's memory. Another young patient, seeing what we were doing, let go of her balloon too. As the balloons faded into the sky, the mother laughed. She said he would have wanted that second choice of balloon.

As we reentered the hospital, walking along the long corridors, passing clinics and waiting rooms, we reminisced about her son. He had an old soul that was beyond his few years on earth. We laughed about the way he played the drums with such a vigor and passion, often waking up other patients on the unit. We reflected on the more difficult times where symptom management was more challenging for him and his mother. I shared with her what a great mother I thought she was and how I admired her strength in such trying times. As we said our goodbyes, she stopped me and said "Thank you for being a part of our lives here." I smiled back and replied, "I was so honored to be a part of it."

Working with terminally ill children and adolescents is complicated. As clinicians, we are called to be empathic resonators, comforting patients and families in some of their most challenging moments. Furthermore, "each patient's life is unique, as is each person's death. How each music therapist responds to patient death is also unique" (Sluzewski, 2011, p. 50). The work

calls for community, a sense of place, and compassion for others, as well as for one's self. If your experience has been anything like mine, there will be days where the work feels extremely draining and debilitating. In moments of intense patient and family suffering, it can be difficult to remain open and empathic to their needs without over-identifying and internalizing such pain. It is a fine line.

However, I would be remiss to not share the joys and the therapeutic relationships that can develop through music in these same moments. I feel extremely privileged to be a music therapist working with patients who are terminally ill. Every day, their stories and their inner resiliency continue to shape me as a clinician. Through the tears, or laughter or quiet reflection it brings, I am reminded that music plays a vital role in end-of-life care. We are granted a gift as music therapists and can truly affirm the music we share with our patients should not be judged by the duration of its notes but the richness of its contents. Let us not forget the responsibility that accompanies this, to take care of ourselves, as we wish to take care of our patients.

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Reflection

As a young music therapist working with terminally ill children and adolescents, I often find myself struggling with frequency of loss I experience. The high acuity of my patients and the powerfully emotional moments I am present for have influenced me both personally and professionally. I was sure that this issue must arise for other clinicians as well, even though it is seldom discussed. The purpose of this project was to research how other healthcare professionals cope with the loss of pediatric patients. I sought out helpful information and concrete exercises aimed to prevent burnout and address compassion fatigue. I recognized that only by attending to this issue would I be able to better sustain a long-term and meaningful practice.

Creating this project has helped me grow exponentially as a clinician. Throughout this endeavor, I was able to process my thoughts regarding end-of-life and my role as a music therapist working with terminally ill children and adolescents. I related with other health-care professionals and experienced a greater connectedness to my peers and the overall medical environment. Through the research and composition portions of this project, I noticed a greater confidence in my academic skills. It has strengthened my confidence in seeking out, reading and utilizing peer-reviewed articles in an effective and meaningful way. This will continue to serve me as I embark on possible research studies on projects in the future.

Dr. Tracy Richardson, MT-BC, Peter Meyer, MA, MT-BC, and Brian Schreck, MA, MT-BC provided guidance and support for this clinical project. Each agreed that the addition of musical wellness was imperative for music therapists. If we do not nurture our own musical needs, we are less able to do so for others. Tracy suggested the idea of an additional worksheet for individuals to explore various hobbies. I see how this could be beneficial and provide a more concrete way to evaluate the effectiveness of the hobbies that one experiments with. Peter was especially helpful in reminding me to speak in an active voice, rather than a passive one –

removing “there are” from my vocabulary! Brian provided an invaluable voice and perspective, as a music therapist working in this same population. I was encouraged that others shared my feelings and that this book could support the work other music therapists in this setting.

If I were to start this project again, I would have focused on pediatric literature from the beginning, rather than trying to encompass all end-of-life-care. I would have also benefitted from creating a concrete template earlier, rather than hoping it would somehow arrange itself in a meaningful way on its own. Once completing this initial outline, I was surprised how much less work the process became. I was able to better see how all the components fit together. This format has also allowed me to see parts of the puzzle that could continue to be expanded upon later down the road.

It is my deepest hope to continue working on this project and to one day publish the workbook for other music therapists to use. As I am still a young clinician, I realize that my attitudes and ideas about end-of-life care will continue to evolve and change over time. Before publication, I would like to continue adding concrete exercises and interventions for self-care and/or processing. I also would like to compile case-vignettes from myself, as well as other music therapists. These could provide a unique perspective on others’ encounters and could also be helpful for music therapists who are considering working in this type of setting. I also hope to find ways to broaden this to include similar disciplines such as creative arts therapist and music therapists working in adult palliative care and hospice.

Through the completion of this clinical project, my passion for this topic has continued to grow. I feel empowered to continue my work as music therapist in this type of setting. I recognize the honor that accompanies working with individuals at end-of-life. In the same regard, I appreciate the responsibility that follows. I must learn to take care of myself, to know

what I need personally and professionally, while remaining open and present to those I care for in the work place.

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