

HEARTBEAT RECORDINGS IN MUSIC THERAPY: A SEQUENTIAL-
EXPLANATORY MIXED METHODS STUDY

A Thesis
by
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Abstract

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Heartbeat recording projects—the combination of a patient’s recorded heartbeat and a meaningful music recording—are becoming popular in music therapy practice. These projects can provide a meaningful representation of a patient’s identity, especially in the context of a legacy project when a patient is nearing death. Despite the appeal of heartbeat recordings, there is minimal research about how they are being used in clinical practice. This study used a sequential-explanatory mixed methods design to better understand the current practice, clinical use, potential barriers, and ethical implications of heartbeat recording projects in music therapy. An online survey was distributed to 8,962 board-certified music therapists. The survey data was collected and analyzed through Qualtrics and informed the questions for the semi-structured interview. Survey respondents with at least one year of experience using heartbeat recordings in music therapy were invited to participate in this interview. Of those who expressed interest, three survey respondents were selected to participate in the follow-up interviews, which provided opportunity to elaborate on the topics addressed by the initial survey based on informants’ personal experiences with heartbeat

recordings in music therapy. The final transcripts of the interviews were analyzed with a thematic analysis, and findings from the survey and interview data were applied to the initial research questions.

Results of this study indicated that while there may be some barriers to learning how to use the intervention, heartbeat recordings are nevertheless being used across all regions of the American Music Therapy Association in a variety of populations for a variety of clinical goals not limited to legacy work. The results of this study also suggest that music therapists must navigate a balance in the process and product, especially when desire for a product is high and patients are near end-of-life, and that music therapists can also be creative in their introduction and use of the intervention. Additionally, music therapists may need to consider difficult questions of copyright issues, cultural sensitivity, and how the heartbeat recording may act as a representation of a traumatic time. Music therapists may also need to provide education to administration or interdisciplinary teams before using the intervention. It is hoped that the results of this study will provide important information for board-certified music therapists interested in incorporating heartbeat recordings in music therapy into their clinical practice. Further research is recommended on topics related to the use of heartbeat recordings in music therapy, including the various uses of heartbeat recordings not limited to legacy work, the importance of rapport and a process-oriented approach, the non-musical product of the recording of the heartbeat alone, and the cultural appropriateness of heartbeat recordings.

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Chapter 1: Introduction

The heartbeat is the sound that results from valves opening and closing as chambers of the heart contract and release. For many people, it is a sound and symbol of life. There is a natural companionship between the heartbeat and music. Music affects our physiological systems, including our heart rate, and words like *beat* and *pulse* can be found in either subject. Music therapists are beginning to draw upon this connection by combining music with a recording of an individual's heartbeat, often in legacy work meant to creatively represent that person's life. For individuals receiving hospice and palliative care and their families, these heartbeat recordings can bring comfort and aid the search for meaning during the grieving process (Schreck & Economos, 2018). Despite the popular appeal of the product, little has been written about the clinical use of heartbeat recordings in music therapy. The purpose of this study is to describe the current practice and clinical use of heartbeat recording projects as a music therapy intervention. This chapter contains information about the fields of music therapy and hospice and palliative care to establish a context for the intervention, as well as definitions of relevant terms.

About Music Therapy

Music therapists have a specialized area of knowledge that distinguishes them from other music professionals (AMTA, 2020a). This knowledge includes a working understanding of music, including music history, theory, composition, repertoire, conducting, and movement, as well as functional music skills in voice, piano, guitar, and percussion.

These skills ensure that music therapists can use music in a pleasing and flexible way, but requirements for music therapy extend beyond the basics of musicianship. As experts on musical behavior, music therapists understand how music can be an expression of psychological and physiological aspects of a person. Music therapists also have a working knowledge of individual and group dynamics and processes within a therapeutic relationship, including an understanding of the role and boundaries of therapist and client, influential aspects of identity and culture, and use of therapeutic dynamics to achieve therapeutic goals. They conduct assessments to determine the client's strengths and needs, emotional and behavioral responses to music, musical preference, and development, and establish and implement a treatment plan based on these assessments. Music therapists use therapeutic verbal skills and a variety of music therapy experiences to support progress toward the established goals. They also collaborate with other professionals in support of the client and evaluate and document the client's progress throughout treatment, revising goals or terminating treatment as appropriate. Like other credentialed professionals, music therapists integrate available research into their practice and participate in multiple forms of supervision and continued education (AMTA, 2020a).

About Hospice and Palliative Care

While compassionate care for dying people has existed informally throughout history, the idea of hospice, a comfort-focused care for people who are dying, only truly began to take hold when Dame Cicely Saunders, a nurse, social worker, and physician, started St. Christopher's Hospice in London in 1967 (McDonald, 2018). Dame Saunders's ideas spread globally and in 1978, the National Hospice Organization, which later became the National Hospice and Palliative Care Organization (NHPCO), was established in the United States

(NHPCO, 2020a). Hospice quickly garnered federal support and in 1982, Congress created a Medicare hospice benefit. Many third-party insurance companies began to add hospice benefits, which increased access to hospice services. Research into hospice care began to grow, and researchers discovered that patients receiving hospice care live an average of 29 days longer than those who do not receive hospice care (Connor et al., 2007). Another study released the same year showed that hospice services save Medicare an average of \$2309 per hospice user, partially due to reduced need for hospitalizations (Taylor et al., 2007). Hospices are in a unique position of saving Medicare money while also improving patient quality of life, and as such, hospice care has continued to expand (Kelley et al., 2013). In 2018, over 1.5 million Medicare beneficiaries in the United States received hospice care services (NHPCO, 2020b).

Palliative care originated from, and is still closely linked to, the hospice movement. Initially, the focus of palliative care was palliation of symptoms in people diagnosed with cancer, but this broadened to include other illnesses. In 1990, the World Health Organization published a report clarifying the distinction that palliative care, unlike hospice care, was appropriate early in the course of treatment and in conjunction with curative care. Hospitals are primary providers of palliative care, but many organizations do provide both services. Like hospice care, palliative care services can improve quality of life while saving hospitals and payers money (Center to Advance Palliative Care, n.d.). In 2016, 75% of hospitals with 50 or more beds reported having a palliative care program (Center to Advance Palliative Care, 2018).

Hospice and palliative care services are also provided to children, though children make up a small percentage of those receiving care from hospice and palliative organizations

(NHPCO, 2015). In 2007, 78% of hospices in the United States who responded to a survey reported that they served pediatric patients, and 36.6% of all hospices who responded had a formal pediatric program (NHPCO, 2015). Pediatric palliative programs are more common in children's hospitals; in a 2013 survey of 162 children's hospitals, 69% reported that they had a pediatric palliative care program (Feudtner et al., 2013). It is possible that the high concentration of children with terminal illness in hospitals is more likely to warrant a specialized palliative care team. While pediatric hospice facilities exist internationally, very few currently exist in the United States (NHPCO, 2015).

For those who qualify for Medicare/Medicaid and are eligible for hospice, Medicare/Medicaid covers all hospice expenses related to the terminal illness, including care provided by the interdisciplinary care team, medication related to the terminal illness, necessary durable medical equipment, grief counseling, short-term inpatient care for symptom management, and other services needed to manage pain and other symptoms as deemed necessary, such as physical or occupational therapy, dietary counseling, and more (U.S. Centers for Medicare & Medicaid Services, n.d.). For individuals who do not qualify for Medicare/Medicaid, most private insurances have a hospice benefit that offers some coverage (American Cancer Society, 2021). For individuals without private insurance, many hospices work out a private pay system often funded by donors. Music therapy does not receive direct reimbursement from Medicare at this time although it has been covered as part of a Medicare Prospective Payment System package (AMTA, 2012); it is largely funded privately by each hospice organization through donors.

Definition of Terms

Music Therapy

As music is generally acknowledged to be a therapeutic tool, it can be easy to assume that any application of music is *music therapy*, but this is incorrect. AMTA defines *music therapy* as the “clinical and evidence-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” (AMTA, 2020b, para. 1). Like other established healthcare professions, music therapy involves a process of assessment, treatment planning, implementation, and documentation. Music therapists use patient-preferred music and adapt music and music interventions to meet the physical, social, emotional, cognitive, or spiritual goals of the patient established during assessment. Music therapy is used in a variety of settings including medical, mental health, geriatric facilities, children’s facilities/schools, and private practice (AMTA, 2020c).

Many individuals and professionals use music in therapeutic and valuable ways that are not music therapy. A nurse might play music for a hospice patient while taking vitals or an older adult might reconnect with favorite songs on an iPod. Professionals like music thanatologists, harp therapists, and music practitioners obtain their own certifications to use music in beneficial ways, and some hospices use music volunteers to perform music in a lobby or at bedside (AMTA, 2004).

Board-Certified Music Therapist

A *board-certified music therapist* (MT-BC) is a professional who is qualified to provide music therapy services. Music therapists must hold a bachelor’s degree or its equivalent in music therapy from an AMTA-approved program, complete 1,200 hours of

clinical training, and pass a board-certification exam administered by the Certification Board for Music Therapists to obtain the MT-BC credential (AMTA, 2020d). Music therapists must recertify every five years, which involves accrual of continuing education credits (AMTA, 2020e).

Hospice and Palliative Care

Hospice Care. *Hospice care* provides people facing end-of-life with holistic comfort-focused care addressing the patient and family's physical, spiritual, and emotional needs through an interdisciplinary team comprised of physicians, nurses, hospice aides, social workers, bereavement and spiritual counselors, volunteers, and occasionally speech, physical, and occupational therapists (NHPCO, 2020a). In order to be eligible for hospice care, an individual must have 6 months or less to live as determined by a physician and no longer be seeking curative treatment (Hospice Foundation of America, 2018). Additionally, the patient must continue to show decline; after 6 months, the hospice team will assess eligibility to remain on hospice care. Hospice provides expert medical care in attending to pain management, comfort, and quality of life. Hospice care is usually provided at the patient's home but can also be provided at a nursing home, residential facility, hospice home, or even a hospital when the patient is receiving respite care or care for acute symptom management (NHPCO, 2020a). Hospice organizations do not discriminate based on age, religion, race, gender, or orientation. While a physician's order is required for hospice eligibility and a physician may recommend a particular hospice organization, individuals have the right to choose any local hospice organization to provide this care and may switch to a different organization once per eligibility period or revoke hospice services at any time (NHPCO, 2021a, 2021b).

Palliative Care. *Palliative care* offers comfort-focused care to individuals with serious illness regardless of prognosis and, in contrast to hospice care, concurrent with curative treatment (NHPCO, 2019). While a palliative team can resemble the hospice interdisciplinary team, it is typically limited to a physician, nurse practitioner, and nurse with consultations to social work and chaplaincy as needed (NHPCO, 2019). The palliative team can assist the patient and family in navigating treatment options, advance care planning, and available resources at a time when choices might be overwhelming (NHPCO, 2019). Medicare/Medicaid covers palliative care but does not cover all treatments and medications and may also require a copay. Most private insurances have a palliative benefit but may differ in coverage, require a copay, and exclude some medications and treatments (NHPCO, 2019).

End-of-life and Terminal Illness

Medicare defines *terminal illness* as an illness that results in a “life expectancy of 6 months or less” (U.S. Centers for Medicare and Medicaid Services, n.d., para. 1). While there are no firm parameters for the definition of end-of-life, it generally refers to the state of having an “irreversible disease with a limited prognosis” (Hui et al., 2014, p. 86). Being at end-of-life or having a terminal illness does not necessarily imply that one is receiving hospice or palliative care, as one might receive standard medical care or decline any medical care but still be terminally ill or at end-of-life.

Imminent Death/Actively Dying

Definitions of *imminent death* and *actively dying* are scarce but tend to refer to the time period of several hours to several days of rapid decline prior to death (Hui et al., 2014). This time is accompanied by physical changes such as cooling of the extremities, slow or

irregular breathing, increased sleeping, increased secretions, and confusion or restlessness (Marrelli, 2018). The individual may have glassy eyes or appear unresponsive but is still able to hear, and these physical changes may not all be present, may occur at different times, or may come and go (Marrelli, 2018). This is often a difficult time for close family and friends as they anticipate the death of their loved one (Krout, 2003).

Grief and Bereavement

Grief is the emotional response to a loss. Grief can be accompanied by physical symptoms such as weight loss/gain, sleeplessness, and anxiety. Grief can also occur prior to the death of a loved one, which is known as *anticipatory grief*. While Kubler-Ross (1969) first introduced the theory that there are stages of grief that include denial, anger, bargaining, depression, and acceptance, it is generally acknowledged that grief is an individualized experience that different people respond to in different ways (Krout, 2003). *Bereavement* refers to the time period when one has experienced a loss (Krout, 2003). Thus, a bereaved person is one who has recently experienced a loss and may be grieving.

Legacy Work

Legacy work is the “process of patients creatively expressing and documenting their lives with the goal of leaving something of themselves for future generations” (Cadrin, 2006, p. 109). Within music therapy, this type of intervention can help individuals find meaning, purpose, and value, say goodbye, gain insight into life experiences, share messages and advice, and find a “sense of completion” (p. 135). While legacy work can occur at any time, it is most relevant at end-of-life due to the questions of meaning and purpose that arise at that time. Legacy work culminates in an object to be left behind or given away, also known as a “legacy project.” These projects take many forms, including but not limited to recordings of

performances by the patient, recordings of patient-composed songs, recordings of patients sharing memories inspired by music, or CDs of dedicated music selected by the patient (Baxter & O’Callaghan, 2010). While the goal of legacy work broadly is to express the meaning and purpose of one’s life in an object, it can also contain messages and wishes for loved ones.

Heartbeat Recording Project

A *heartbeat recording* is an auditory capture of the opening and closing of valves in the heart. These recordings are used within medical settings to determine how the heart is functioning; however, as the heartbeat can be a symbol of life, heartbeat recordings also have the potential to hold greater meaning. The use of heartbeat recordings in music therapy legacy projects was conceptualized by music therapist Brian Schreck for use with infants and children, but its use has since expanded across age ranges to include teens, adults, and older adults. Schreck combined audio recordings of the patient’s heartbeat with a prerecorded or recreated version of a *song of kin* (Loewy, 2015), which is a song that is meaningful to the patient and/or family (Schreck & Economos, 2018). Schreck’s method involved a multi-step process of (a) recording a perinatal or post-birth heartbeat, (b) editing this heartbeat to create the desired heartbeat loop, (c) selecting or composing a meaningful song and recording it, and (d) combining the heartbeat recording with the selected song. The product was then given to the patient and/or family who may then listen to the project as desired. Schreck found that the intervention could be used “to celebrate the baby’s life in utero, unite the family in a shared experience, comfort the mother during labor, and facilitate legacy work” (p. 24). This intervention has gained some popularity in social media and the press (Associated Press, 2016; CareDimensions, 2018; Cincinnati Children’s, 2014; Lantz, 2017)

and is now being used by more music therapists. For the purposes of this paper, *heartbeat recording project* will refer the use of a heartbeat recording in combination with other forms of media for use in music therapy.

Chapter 2: Literature Review

While literature about the use of heartbeat recordings in music therapy is sparse, the intervention seems to have grown quickly in popularity and was even included as an intervention on one recent survey of music therapists working in pediatric medical settings (Knott et al., 2020). Available literature situates heartbeat recordings in perinatal and pediatric end-of-life care at a children's hospital, but it has also been presumed to be useful in hospice and palliative care more broadly (Clements-Cortés, 2017). This chapter begins with a summary of the available literature on heartbeat recordings in music therapy, followed by an overview of music therapy in both adult and pediatric hospice and palliative care. Next, since heartbeat recording projects exist as a form of legacy work with patients and families, this chapter considers the unique role of family and caregivers in music therapy within these settings. Finally, because heartbeat recording projects require the use of technology, an overview of the use of technology in music therapy is presented.

Heartbeat Recordings in Music Therapy

Following Schreck and Economos's (2018) article describing the use of heartbeat recording projects in perinatal hospice music therapy, literature has solely focused on how heartbeat recordings affect bereaved parents. Walden et al. (2020) conducted interviews with 11 parents of children with progressive neurodegenerative illness three months after they received a heartbeat recording project to better understand how heartbeat recording projects were being used by the patient's bereaved family. The researchers found that heartbeat

recordings helped the parents with meaning-making of the child's life, expression of grief, and coping. It was recommended that as families cope with grief and bereavement in different ways, the families themselves should determine whether a heartbeat recording would be meaningful or comforting. Andrews et al. (2020) surveyed 11 families to determine how legacy projects, particularly in the form of heartbeat recording, were presented to parents, their levels of satisfaction with the project, and how they utilized the project. Researchers found that families heard about the intervention through their palliative physician, music therapist, or child life specialist. The heartbeat recording projects were well received by all participants, and the recordings were used to varying degrees, from daily to less than monthly.

Music Therapy in Adult Hospice and Palliative Care

Music therapy is used in hospice and palliative settings to holistically improve quality of life and transition to death. Hospice music therapists support the physical, emotional, social, and spiritual needs of their patients through a variety of music-based interventions. Music therapy is a well-established field within end-of-life care; a national survey of hospices in 2008-2009 found that 53% of hospices employ a music therapist (Dain et al., 2015). According to the 2020 AMTA Workforce Analysis, over 130 board-certified music therapists currently work in hospice and bereavement services (AMTA, 2020c). While music therapy services are not reimbursable by Medicare, they may be cost effective for hospice organizations. A cost/benefit analysis by Romo and Gifford (2007) found that for a small sample of 16 patients, music therapy resulted in a cost savings of \$2,984 when compared to standard care for patients. Because the cost of the music therapy program was \$3,615, the cost-benefit ratio was .83 for the 9-month period of the study, demonstrating a loss, but when

considering cost per patient day, the cost-benefit ratio was .95 and indicated that “savings may be even greater in the wider patient population” (p. 357). Romo and Gifford’s calculations point to a reduced need for medication and visits from other clinical staff when a patient is receiving music therapy services.

Music Therapy as a Complementary Therapy in Hospice Care

In many hospice organizations, music therapy is designated as a “complementary therapy” alongside modalities such as acupuncture, Reiki, and aromatherapy. As the interest in and legitimization of complementary therapies has grown, so has funding and access to these services (Zeng et al., 2018). While the designation of music therapy as a complementary therapy may increase access to services, some researchers argue that music therapy should be more centrally located within the core hospice team rather than a complementary service. When music therapy is categorized as a complementary therapy and is associated with non-evidence-based practices, patients and health care professionals may question its use in end-of-life care (Potvin et al., 2018).

Music Therapy Goals and Interventions in Hospice Care

Hospice music therapists most commonly address anxiety and pain but also care for a wide variety of physical, emotional, and spiritual needs (Bowers & Wetsel, 2014). Music therapists have described effectively addressing physical needs such as pain management (DiMaio, 2010) and relaxation (Nicholson, 2001) with music therapy. Interventions such as music imaging (Abrams & Kasayka, 2005), lullabies (Loewy & Stewart, 2005), music meditation (Chestnut et al., 2005), and entrainment (DiMaio, 2010) are often used to meet these physical needs.

End-of-life can be an emotionally difficult time, and hospice music therapists are trained to provide emotional and spiritual support. Hospice music therapists have described working with patients to meet emotional needs such as improving quality of life (Hilliard, 2005a), supporting a patient's ability to cope (Hanser, 2005), and supporting the expression and exploration of emotions (Clements-Cortés, 2004; Heath & Lings, 2012). More specifically, music therapists work with patients to address relational issues to aid in relationship completion prior to death (Clements-Cortés, 2010; Dileo & Parker, 2005) and to help patients and families with anticipatory grief (Mondanaro, 2005). When a patient is close to death, music therapists can provide support during transition to death (Loewy et al., 2005). Often, spirituality is a strong resource for patients at end-of-life, and music therapists can support an enhanced connection to their higher power (Magill, 2005). For these types of goals, music therapists will often use interventions such as songwriting (Heath & Lings, 2012; Krout, 2005; O'Callaghan, 2005), singing (Clements-Cortés, 2017; Hilliard & Justice, 2012), improvisation (Cadesky, 2005), or life review (Beggs, 2012). Music therapists also use techniques that require advanced training, such as the Bonny Method of Guided Imagery and Music (Cadrin, 2009; Clements-Cortés & Klinck, 2016).

Research About Music Therapy in Hospice and Palliative Care

Research examining the efficacy of music therapy in a hospice and palliative care setting is somewhat limited. The majority of research focuses on measures related to the physical body such as stress, anxiety, pain, comfort, and relaxation. Nakayama et al. (2009) investigated the effects of music therapy on levels of stress in hospice patients in Japan. Salivary cortisol levels of the 10 participants were measured before and after a 40-minute music therapy session. Participants also completed a mood inventory before and after the

session. Results showed a decrease in stress for participants as a result of a single music therapy session. Horne-Thompson and Grocke (2008) discovered a similar decrease in anxiety levels of patients who were terminally ill in response to music therapy. In this randomized control trial, researchers measured anxiety in 25 participants via heart rate and the Edmonton Symptom Assessment System. A significant reduction in anxiety was found in the experimental group receiving a single music therapy session. Finally, Krout (2001) conducted a clinical effectiveness study involving 80 hospice patients to determine the effects of a single session of music therapy on pain, comfort, and relaxation. Data were gathered by self-report and observation and indicated that music therapy was effective to reduce pain and increase comfort and relaxation.

Research has also explored the benefits of music therapy on aspects of wellbeing in hospice patients. Wlodarczyk (2007) found that spiritual well-being increased on days when patients received music therapy in a sample of 10 hospice patients. Hilliard (2003a) studied the effects of music therapy visits on quality and length of life in 80 hospice patients. While length of life was not affected, quality of life increased for participants receiving music therapy.

Reviews of literature suggest that music therapy may be effective to increase quality of life and provide symptom relief at end-of-life. Through a review of empirical data, Hilliard (2005b) found that music therapy may decrease anxiety and discomfort, increase spiritual well-being, and increase perceived quality of life. In a 2011 Cochrane review, Whitehead determined that music therapy may improve quality of life and provide some symptom relief, but results were not significant due to limited evidence. McConnell et al. (2016) updated a 2010 Cochrane review by Bradt and Dileo that established that music therapy may be

effective to improve quality of life. The update by McConnell et al. added that music therapy may be effective in reducing pain among palliative care patients. Most recently, Gao et al. (2019) conducted a meta-analysis of randomized control trials on the effectiveness of music therapy to meet physiological and psychological needs of individuals receiving end-of-life care. Their analysis demonstrated that music therapy in hospice and palliative care was effective to increase quality of life and to reduce pain, anxiety, and depression, but noted a need for more high-quality randomized control trials.

While these findings are promising, some researchers argue that there is a high degree of bias in music therapy literature (McConnell et al., 2016; Whitehead, 2011). Additionally, there are very few large-scale studies which are preferred for an evidence-based approach. McConnell et al. concluded that “this lack of evidence highlights an urgent need for methodologically rigorous trials of clearly defined music therapy interventions with common outcome measures” (p. 881). Given this, it is relevant to note that the essentiality of quantitative data is challenged by some researchers who believe qualitative research is best suited to “ethically and meaningfully sound these collective voices” (O’Callaghan & Barry, 2009, para. 36).

Music Therapy in Pediatric Hospice and Palliative Care

Literature on the use of music therapy in pediatric hospice and palliative care is sparse and largely anecdotal. Despite this, music therapy does appear to be well received. The United Kingdom has seen an increase in provision of music therapy at children’s hospices (Hodkinson et al., 2014). Similarly, a survey by Knapp et al. (2009) found that parents whose child received music therapy through a pediatric palliative program in the United States were more likely to be satisfied with the program.

Several researchers have produced qualitative literature describing the process and benefits of music therapy work with this population. While pediatric patients at end-of-life require physical, emotional, social, and spiritual care similar to adult clients, this population also has unique needs. Music therapy can aid children in expressing and exploring feelings related to their illness (Daveson & Kennelly, 2000) and can also be used to reduce pain perception through non-pharmacological techniques (Duda, 2013). Pediatric patients also need normalcy and opportunity for fun and play (Hilliard, 2003b), as well as the chance to “interact in a ‘non-patient manner’” (Daveson & Kennelly, 2000, p. 37), which can all be provided through music therapy. Finally, in a setting where opportunities for choice and control are limited, music therapy can provide these opportunities through instrument play, song choice, and a variety of other interventions (Sheridan & McFerran, 2004). Legacy work, which will be discussed later in this paper, also is used in pediatric hospice and palliative music therapy.

There is a dearth of quantitative literature on the use of music therapy in pediatric hospice and palliative care. One mixed-methods exploratory study was conducted to determine the effects of live and vibroacoustic music therapy on pain, distress, and contentment in children with neurological impairments who were receiving palliative care (Clark et al., 2017). However, a ceiling effect in the data meant that the researchers were not able to draw a conclusion.

Involvement of Caregivers and Family in Hospice and Palliative Music Therapy

Care for the family is an integral aspect of hospice and palliative care (NHPCO, 2020a). Support and education are regularly provided to family caregivers as they care for their loved one, including education about the dying process, opportunities for grief

counseling, and regular assessment of the caregiver's needs. In music therapy, the family is often a part of the services provided. Families appreciate the comfort and stimulation as well as the shared, positive experiences in music (Lindenfelser et al., 2012). Kim and Dvorak (2018) compared the effects of music therapy and chaplaincy on affective, verbal, and physical intimacy between caregivers and their dying loved one. They concluded that affective and physical intimacy was higher in recipients of music therapy, suggesting that music therapy may be useful to enhance this important relationship. No difference was observed in verbal intimacy, but individuals receiving music therapy showed more verbal behaviors of "letting go of [the] patient" in music therapy versus chaplaincy (p. 227). Savage and Taylor (2013) found that music therapy may encourage expressions of care between family and patient, such as smiling, eye contact, kisses, and moving closer. While patients and caregivers benefit from being supported together by music therapy, they also experience individual benefits. According to Gallagher et al. (2017), 82% of family members report improved stress, mood, and quality of life as a result of music therapy, and patients reported improved pain, depression, distress, and mood.

Flower (2008) described through case studies three frameworks that might be present in the therapeutic relationship when working with children near end-of-life and their families. First, the parent might be an "active observer" (p. 188), while the child and music therapist maintain the primary relationship. Second, the music therapist might meet and support the family in playing music together, providing a space for the family to be together. Third, the music therapist might focus support on the parents, enabling them to express love to the child in music. Flower concluded that a flexible approach to work with children and their families at end-of-life is most appropriate.

Family-centered care has also been used in music therapy work in the neonatal intensive care unit (NICU) as a way for families to create memories, face the uncertainty of death, and provide ritual (Ettenberger, 2017). Loewy examined family-based interventions when studying the effects of a “song of kin” (2015, p. 178) intervention in the NICU setting. This intervention involves the selection and singing of a familiar or meaningful lullaby by the child’s parents. Parents were instructed to match the baby’s breathing and activity level when singing, a process known as entrainment. Not only did the use of the song of kin intervention result in increase of sleep time and decreased heart rate of the infant, but parental stress also decreased. Forrest (2014) noted that it is especially important when working in a family-based care model to maintain cultural competency and “consider the cultural *song* of the family” (p. 24).

Some researchers have interviewed bereaved caregivers to gather their unique perspective on music and music therapy. Caregivers have shared that music therapy has the potential to alter their perception of the difficult end-of-life experience, create opportunities for remembrance, create a multifaceted experience for the patient and family, and communicate and express feelings (Lindenfelser et al., 2008). Music, specifically, can act as a conduit to connect with memories, places, and loved ones, something that has potential to affect our neurophysiology and foster a connection to love (Magill, 2009). Caregivers use music to improve mood and to energize, but also to remember the deceased, grieve, and continue the relational bond through memory. Caregivers might also avoid music in order to avoid intensifying sadness (O’Callaghan et al., 2013).

Music Therapy Legacy Projects

There is limited literature about legacy work in music therapy, but the available research does examine some of the clinical applications of legacy work and the different forms these projects can take. Cadrin (2006) described the nature of legacy work with three different patients. In the first case example, the patient and family created a music video together. This video included the family sharing important messages and singing songs that represented the role of music in their lives, such as the way music was an expression of love and always brought them together. Cadrin followed up with the family a year after the patient's death to learn how the music video and their father's legacy was present in their lives. While some family members felt that it was too soon to watch it or they "had to be ready to watch it" (p. 123), others found comfort in the video, and one stated that she realized, "The music didn't die. Dad is still here." (p. 124), indicating that the project supported the continuation of their relationship after the patient's death. In the second case example, Cadrin and the patient co-wrote a song detailing the patient's philosophy of life for her husband and 3-year-old daughter. The patient was recorded singing the song, which was given to the family following her death as requested. This project allowed the patient to convey her values, gain a sense of closure, and offer advice to her daughter. In the third case study, Cadrin described how a patient journaled about spiritual insights, life experiences, and wisdom gained from modified sessions of the Bonny Method of Guided Imagery and Music. These legacy journals were distributed to friends and family after her death. This project allowed the patient "to review her life, to gain insights to the experiences she had lived through, and to share words of guidance and gratitude" (p. 130).

Songwriting as a form of legacy work holds potential to convey significant messages to a loved one. O'Callaghan et al. (2009) analyzed themes in the lyrics of 35 songs written by parents at end-of-life for their children. The resulting themes included "love; memories; yearning for children; metaphysical presence (now and afterlife); loss and grief; the meaning and helpfulness of the children in their lives; hopes for and compliments about their children; encouragement; requests; personal reflections; existential beliefs; and suggestions about to whom the children can turn" (p. 1154). O'Callaghan also noted that while songwriting can be cathartic, the song product, especially as it exists in a recorded form, can facilitate continued attachment between parent and child following the parent's death. This attachment can be important for the development of the child. O'Callaghan (2013) later expanded the relevance of this use of legacy creation in relationship continuation beyond the parent-child relationship, affirming that legacy work can be an important aspect of pre-loss care for any relationship, such as friendships or husband-wife relationships.

Baxter and O'Callaghan (2010) addressed ethical and legal questions related to the creation of legacy projects. In particular, they considered the future use and possible consequences of legacy projects. The authors encouraged music therapists to discuss the "future life" (p. 7) of a legacy project with the patient and to utilize consent forms in a project's creation. They recommended patient ownership or joint ownership of the product and proper storage of completed projects, and they suggested offering incomplete projects to the patient's family if a patient dies before it can be completed, and if the family agrees. Overall, Baxter and O'Callaghan encourage an awareness of these potential issues and good communication skills in discussion of the patient's wishes at the start of the legacy creation process.

Theoretical Orientations in Music Therapy

Music therapists work from an array of theoretical orientations, including traditional models drawn from psychology (such as psychoanalytic, person-centered, and cognitive behavioral therapy) as well as those derived from the field of music therapy (such as resource-oriented music therapy and analytical music therapy). Theoretical orientations specifically described in hospice and palliative music therapy literature include aesthetic music therapy (Lee, 2005), analytic music therapy (Scheiby, 2005), environmental music therapy (Schneider, 2005), humanism (DiMaio, 2010), and resource-oriented music therapy (Potvin et al., 2018). There is no literature exploring which orientations are most common in music therapists who use heartbeat recordings.

Music Therapy and Technology

According to descriptions in available literature, heartbeat recordings employ two technologies with which music therapists might not be familiar: a Bluetooth-enabled stethoscope or stethoscope/microphone combination and Garageband, an audio editing software (Schreck & Economos, 2018). Over the past few decades, innovative technology has entered the world of music and music therapy, bringing adapted musical instruments, recording technology, electric/electronic musical instruments, computer applications, medical technology, assistive technology, and more (Crowe & Rio, 2004). Music therapists have continued to advocate for the use of technology in music therapy, even providing overviews of applicable technologies for guidance (Knight & Krout, 2017; Knight & Lagasse, 2012).

Viega (2018) offered guidance on the humanistic use of recording technologies in clinical songwriting with clients that might be applied more broadly to other uses of

recording technologies in music therapy. He also discussed the ability of prerecorded instruments, precomposed loops, and electronic equipment to cultivate agency, and the ways that production techniques such as pitch correction, pitch manipulation, layering, and double vocals can help express the experience of the songwriter. While the available literature situates the music therapist as the one utilizing recording technology in heartbeat recordings, this information can guide clinical decision-making regarding the ways the audio recording might represent the client and/or the client's legacy.

Despite the prevalent use of technology in music therapy, surprisingly little has been written on ethical considerations for practice. Bates (2014) offered an overview of ethical considerations related to e-professionalism, social media, computer-mediated music therapy, and advertising and public relations, but notes that the list is not exhaustive. Bates importantly acknowledged that “as technology and usage changes, new ethical issues may emerge, or the guidelines provided in this article may become outdated” (p. 2014). No other literature currently explores ethical questions related to technology in music therapy or in the use of heartbeat recordings.

Music Therapy and Copyright Law

One area of ethical concern for music therapists is copyright law. Until recently, attention to the question of copyright in music therapy practice was largely the concern of music therapy professionals with few outside parties involved, but literature has begun to advocate for an exemption for music therapy under copyright law. Reid (2020) made a case for a statutory exemption for therapeutic uses of music due to the “socially valuable uses of music therapy, coupled with the high transaction costs to individually license songs and the de minimis lost revenue for not licensing the uses” (p. 4). Reid noted that therapeutic uses of

copyrighted music may fall under fair use, which requires no licensing, but that the case-by-case approach used to determine whether it is fair use is “insufficient protection for therapeutic activities” (p. 42). Reid found that many music therapists feel confused by what can be constituted as fair use. Reid & Miño (2021) conducted 18 interviews with music therapists to understand more about music therapists’ comfort zone with respect to uses of copyrighted music. They found that music therapists are “comfortable using copyrighted music in private sessions” (p. 955) but discourage social media sharing in order to avoid liability and emotional harm if the videos are taken down due to copyrighted content. They also found that music therapists are often torn between meeting patients’ needs, which often requires the use of some form of copyrighted music, and following the law.

During this study, this researcher was contacted by Barbara A. Else, MPA, MT-BC, a consultant to AMTA on matters of copyright who regularly fields questions from AMTA members on this topic. In a follow-up conversation for which consent to include quoted excerpts from the conversation was received, Else stated that she believes that “there may be high variation with respect to professional awareness and understanding of the law presently and how to handle this in practice” and offered a few considerations for music therapists regarding heartbeat recording projects (B. A. Else, personal communication, March 2, 2021).

The law is silent on this question; in fact, copyright law is silent on music therapy as a practice. What we do have on record at AMTA is a letter that our lawyer provided, and it is a dated letter now, with one of the publishers ... that says they believed it was acceptable in private, non-public music therapy sessions to play live a piece of music that is a cover tune covered under copyright. ...

My feedback to folks has been that if [the heartbeat recording] is in the context of a private music therapy session with parents to do the heartbeat recording for their private, personal use, there may well be some leverage to be able to use a copyrighted tune, record it, and make the adjustments that you need to do based on the tempo of the heartbeat. The minute that copies are made and distributed, it becomes a gray area and technically without licensing, you could be breaking the law. ... The reality is that if you are doing a heartbeat recording, particularly with parents for a high-risk infant which turns out to be a legacy recording because the infant dies, and there is some sort of distribution, even limited distribution (i.e., at a funeral/memorial event), the artists may not want to be the ones that are going to raise a red flag about this. Copyright holders may not either. ... It is certainly possible to do some licensing for it as well. The mechanical license could cover them just fine. ...

If somebody pressed it and did a cease and desist, took someone to court, or a music publisher filed a suit, I could see arguments on both sides of the law about whether this is permitted or not. I could see [music therapists] being on the wrong side of the law easily, however. The ultimate risk to the music therapist is they could lose their credential and licensing because it is against our standards of practice and code of ethics. We follow the law. That has never happened, but ultimately that is what is at risk here.

Else also shared that AMTA is working to make a case for an exemption for music therapy under copyright law.

Conclusion

Heartbeat recording projects are being used in pediatric hospitals for legacy work in end-of-life care (Andrews et al., 2020; Schreck & Economos, 2018; Walden et al., 2020), but research on the clinical use of the intervention, especially outside of pediatric hospitals, is sparse. No literature has explored potential issues related to implementation of this intervention, such as the potential training required to operate the necessary equipment and technology. Heartbeat recordings are a new application of technology in music therapy, and necessary equipment and technology have only been briefly described. Finally, relevant ethical questions have not been explored.

Statement of Purpose and Research Questions

The purpose of this study is to describe the current practice and clinical use of heartbeat recording projects as a music therapy intervention. The following research questions have been developed in order to gather insight from board-certified music therapists regarding their use of heartbeat recordings in music therapy.

1. What, if any, are the barriers for music therapists interested in implementing this intervention?
2. Who is using heartbeat recordings as a music therapy intervention?
3. With whom are heartbeat recordings being used?
4. How are heartbeat recordings used in music therapy?
5. What technology is used to create and deliver heartbeat recordings?
6. What are ethical considerations for the implementation of heartbeat recordings and associated use of technology?

Chapter 3: Method

This chapter describes the method of this study, including the research design, instrumentation, and participants. It also describes the procedure, including data collection, analysis, and validity procedures.

Research Design

This study followed a mixed methods sequential explanatory research design, which used two sequential phases of data collection and analysis (Creswell & Plano Clark, 2018). The first phase was the collection of quantitative data, which in this study was collected through a survey (see Appendix A). Data from the survey were then analyzed and informed the second phase, the collection of qualitative data through interviews, which provided insight into the previously gathered quantitative data.

Instrumentation

There was no published survey about heartbeat recordings as an intervention at the time of this study, so the researcher created one. The researcher developed the survey to address research questions which arose after reviewing available literature and noting gaps. The survey included questions about possible barriers to the use of this intervention, which music therapists were using heartbeat recordings, the clinical settings where heartbeat recordings were being used in music therapy, the clinical and technological processes of creating heartbeat recording projects, and variations on how heartbeat recordings are used. The survey concluded with a question inviting participants who currently use heartbeat

recordings in their clinical work to participate in a follow-up interview. The survey was piloted by a convenience sample of experienced board-certified music therapists working as faculty at the investigator's university. Feedback from the pilot was applied to the final version of the survey, which was administered through Qualtrics, an online survey platform.

The researcher also created a guide for semi-structured interviews (see Appendix B) to be conducted following the survey with selected survey respondents who indicated willingness participate in the interview and provided additional contact information. The questions were developed to explore topics that emerged from the survey data. The interviews were conducted and transcribed using Zoom, a videoconferencing program.

Participant Characteristics

Inclusion criteria for this study was individuals holding the MT-BC credential as identified by the Certification Board for Music Therapists (CBMT). Music therapists without experience using heartbeat recordings were included in an effort to gather data on possible barriers to use of this intervention. Individuals who were not board-certified music therapists were excluded from the survey. Individuals who had less than one year of experience using heartbeat recordings in music therapy were excluded from participating in the follow-up interview in favor of individuals who were more experienced with this intervention.

Recruitment

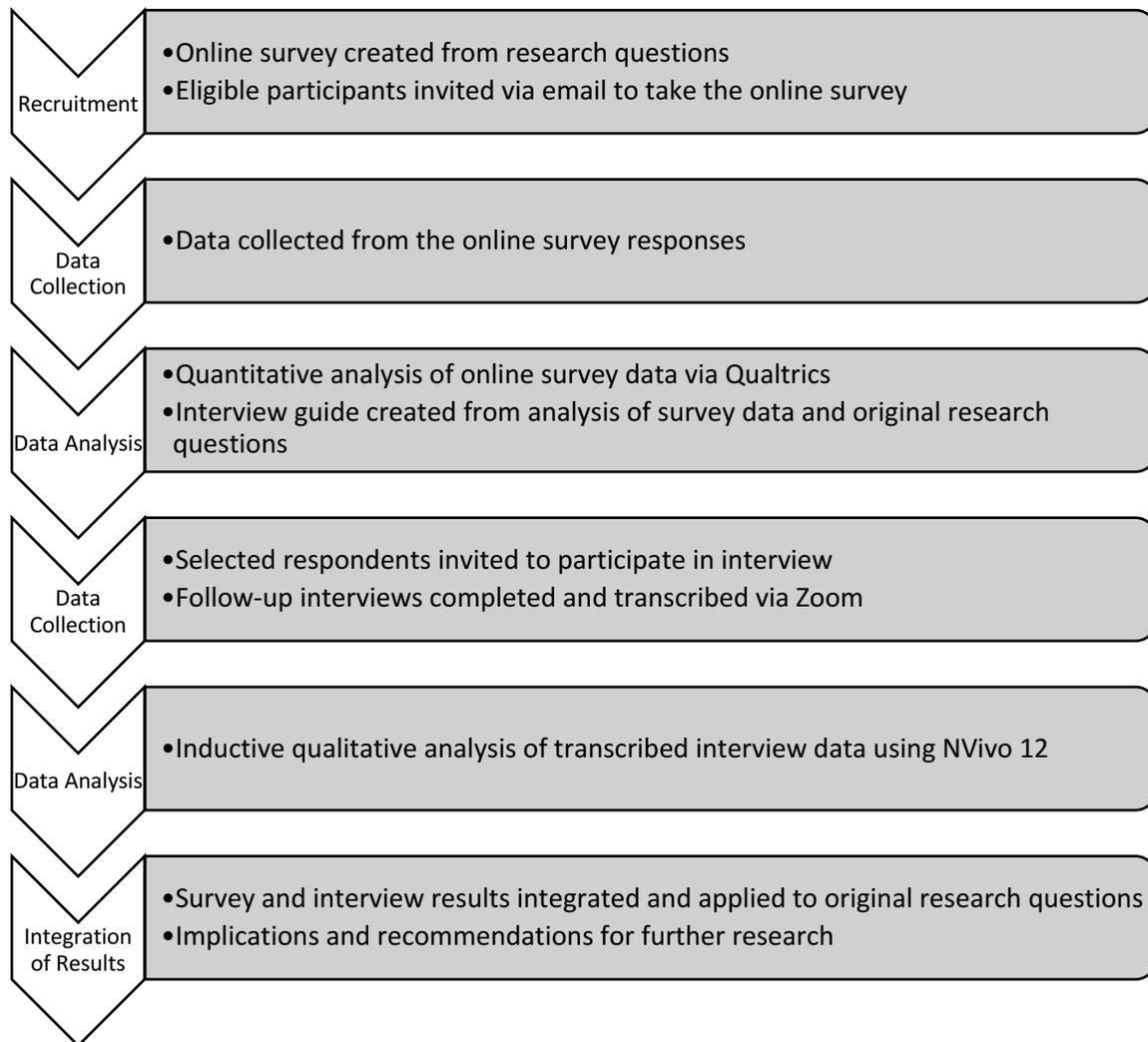
A list of the email addresses of board-certified music therapists was purchased from the CBMT. Participants received an email inviting them to a survey if they had experience with heartbeat recording projects or were interested in using heartbeat recording projects in music therapy. A reminder email was sent two weeks after the initial invitation email. When completing the survey, respondents who had experience utilizing heartbeat recording projects

were also invited to share contact information if they were interested in participating in a follow-up interview. One respondent who expressed interest was purposely selected for the interview because his name was mentioned by survey respondents as someone knowledgeable about heartbeat recordings, as he pioneered the intervention. Other participants who volunteered for the interview were sorted into two categories, medical and hospice/older adults, based on their experience with each population. Then a random number generator was used to select one volunteer from each category.

Ethical Considerations. A statement of informed consent was included in the initial email to potential participants (see Appendix C). Respondents who were selected for a follow-up interview completed and returned an additional consent form (see Appendix D). Confidentiality was maintained and no identifying information was reported with the exception of one respondent who participated in the interview and requested that his full name be used. All data were stored on a password-protected computer. This study was deemed to be exempt from IRB review by the Appalachian State University IRB (see Appendix E).

Procedure

This study followed a mixed methods sequential-explanatory design. It began with a survey (see Appendix A) to obtain a general understanding of the process and application of the heartbeat recording project as a music therapy intervention, barriers to the intervention, demographics of music therapists who use it, and ethical concerns. The survey was followed by semi-structured interviews of selected experienced respondents who volunteered to be interviewed. These interviews invited an in-depth response to topics introduced by the survey. A description of the study flow can be seen in Figure 1.

Figure 1*Flow of the Study****Follow-Up Interviews***

Follow-up interviews were conducted via Zoom. Prior to the interview, participants signed and returned an additional consent form. The interview was conducted over Zoom with the researcher in a private location and the participant in a location of their choice. The interview was recorded and transcribed via Zoom. The researcher corrected any mistakes in transcription following the interview and provided a copy to the interviewee for member

checking. The researcher corrected any further mistakes noted by the interviewee, and this final transcription was used as the qualitative data.

Data Collection and Analysis

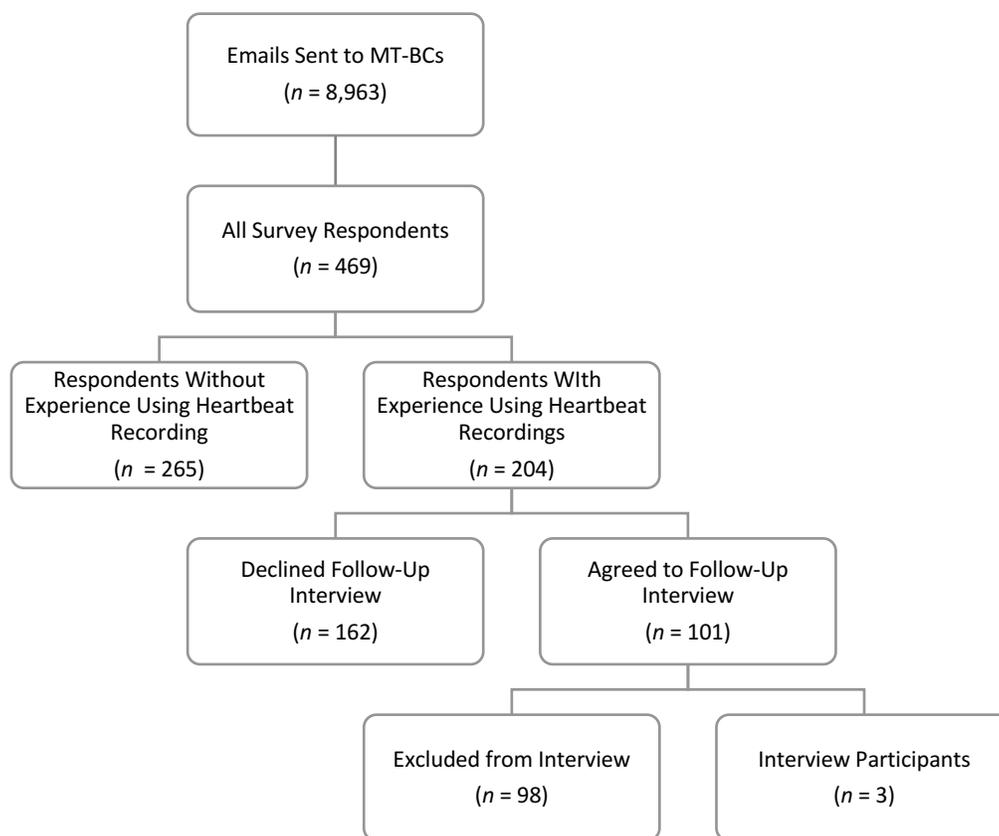
Two sets of data were collected and analyzed: the online survey and the transcribed follow-up interview. Online survey data were gathered and analyzed through Qualtrics using descriptive statistics. The final transcripts of the interviews were analyzed with a thematic analysis using NVivo 12, which was provided by the researcher's university. The researcher analyzed the interviews using a qualitative content analysis approach described by Ghetti and Keith (2016) which is common in music therapy literature. Following this approach, the researcher identified meaning units and created codes in NVivo 12. The researcher then condensed and paraphrased the text of the interviews. Finally, the researcher abstracted and categorized by grouping codes into content areas, themes, and subthemes. While Ghetti and Keith acknowledge that this approach can be inductive or deductive, this researcher followed an inductive approach, allowing themes to arise from the data. Findings from the survey and interview data were applied to the initial research questions.

Chapter 4: Survey Results

This chapter reports the results from the 30-item online survey created by the researcher. Participant characteristics are presented, followed by sections of the survey, which include barriers to the use of heartbeat recordings, the current clinical practice of heartbeat recording projects in music therapy, and who is using heartbeat recordings in music therapy. Both partial and completed survey responses were included in the reported results, resulting in a varied total number of respondents for each survey question.

Participant Characteristics

A total of 8,963 board-certified music therapists who were registered with the CBMT and opted-in to email communications were invited to participate in the online survey. Of those, 469 music therapists responded to the survey, with 39 respondents partially completing the survey and 430 respondents fully completing the survey. Of the respondents, 43.5% ($n = 204$) indicated they had experience with heartbeat recordings in music therapy and 45.5% ($n = 265$) indicated that they did not have experience with heartbeat recordings in music therapy. See Figure 2 for more information about participant flow in this study.

Figure 2*Participant Flow**Respondent Demographics*

Demographic data were gathered on respondents with experience using heartbeat recordings. See Table 1 for a full description of respondent demographics. Of respondents with experience using heartbeat recordings, most identified their gender as female and ethnicity as White. All seven regions of AMTA were represented and respondents included music therapists of all ages, although the majority of respondents were in the youngest age bracket. Similarly, the majority of respondents reported having their board certification for 1-5 years. Almost half of the respondents achieved a master's degree as the highest level of education, which was the most common response. When asked about years of experience using heartbeat recordings, 31% ($n = 60$) of respondents had 2-5 years of experience, 26.8%

($n = 52$) of respondent had 0-1 year of experience, 24.7% ($n = 48$) of respondents had 1-2 years of experience, and 17.5% ($n = 34$) of respondents had 5+ years of experience. Almost half of the respondents described their theoretical orientation as humanistic (see Table 2), followed by eclectic and cognitive-behavioral. While respondents were only able to select one orientation, a number selected “eclectic” and others wrote in multiple orientations under “other.” Write-in responses mentioning multiple orientations or stating that it “depends on the client” were added to the “eclectic” category.

Table 1

Respondent Demographics

Characteristic	Category	Frequency	Percentage
Gender Identity	<i>Female</i>	152	85.4%
	<i>Male</i>	19	10.7%
	<i>Prefer not to answer</i>	5	2.8%
	<i>Non-binary</i>	1	0.6%
	<i>Self-describe</i>	1	0.5%
Age Range	<i>20-29</i>	71	40.1%
	<i>30-39</i>	69	39.0%
	<i>40-49</i>	30	17.0%
	<i>50+</i>	7	4.0%
Ethnicity	<i>White</i>	138	79.3%
	<i>Asian</i>	13	7.5%
	<i>Prefer not to answer</i>	12	6.9%
	<i>Hispanic, Latinx, or Spanish origin</i>	10	5.8%
	<i>Black or African American</i>	4	2.3%
	<i>Middle Eastern or North African</i>	2	1.2%
	<i>Native American or Alaska Native</i>	1	0.6%
	<i>Native Hawaiian or Other Pacific Islander</i>	0	0%
Identify as having a Disability	<i>No</i>	159	88.8%
	<i>Yes</i>	12	6.7%
	<i>Prefer not to answer</i>	8	4.4%

Characteristic	Category	Frequency	Percentage
Region of AMTA	<i>Great Lakes region</i>	56	31.5%
	<i>Southeastern region</i>	37	20.8%
	<i>Western region</i>	26	14.6%
	<i>Mid-Atlantic region</i>	22	12.4%
	<i>Midwestern region</i>	15	8.4%
	<i>Southwestern region</i>	15	8.4%
	<i>New England region</i>	7	3.9%
Level of Education	<i>Master's degree in music therapy</i>	85	47.5%
	<i>Undergraduate degree in music therapy</i>	71	39.7%
	<i>Master's degree in a related field</i>	13	7.3%
	<i>Equivalency in music therapy</i>	7	3.9%
	<i>Doctoral degree in music therapy</i>	3	1.7%
	<i>Doctoral degree in a related field</i>	0	0%
Years as a Board-Certified Music Therapist	<i>1-5</i>	72	40.2%
	<i>6-10</i>	61	34.1%
	<i>11-15</i>	20	11.2%
	<i>16-20</i>	14	7.8%
	<i>21-25</i>	6	3.4%
	<i>26-30</i>	4	2.2%
	<i>31-35</i>	2	1.1%

Table 2*Theoretical Orientation of Music Therapist*

Name	Frequency	Percentage
Humanistic	87	48.3%
Eclectic	48	26.7%
Cognitive-Behavioral	24	13.3%
Other (please specify) ^b	11	6.1%
Neurologic Music Therapist (NMT)	4	2.2%
Existential	2	1.1%
Resource-Oriented Music Therapy	2	1.1%
Gestalt	1	0.6%
Psychodynamic	1	0.6%

^b Responses included Transpersonal (2), Culture-centered (1), Narrative (1), Music-centered (1), Psychodynamically-oriented supportive therapy (1), Integrative (1), Patient-centered (1), Holistic (1), Integrative (1), and “Not familiar with listed orientations” (1)

Barriers to Use of Heartbeat Recordings

Respondents without experience using heartbeat recordings were asked to select barriers to the use of heartbeat recordings in their practice. Respondents were able to select multiple responses. The most common barriers chosen were related to the music therapists' settings or populations not being relevant, followed closely by access to funding for the necessary equipment (see Table 3). Categories were created for similar responses entered via text including "lack of familiarity with the intervention," "privacy concerns," and "questions about benefit." Notable barriers included concerns about copyright and whether recording applications are HIPAA compliant. One respondent also wrote, "I come from a different culture, where doing this is considered inappropriate and creepy."

Table 3

Barriers to the Use of Heartbeat Recordings

Barrier	Frequency	Percentage
I don't work in a relevant setting	120	48.0%
I don't work with a relevant population	106	42.4%
I don't have access to funding for equipment	105	42.0%
I don't know where to find training	82	32.8%
I don't feel comfortable with the technology	57	22.8%
This intervention is not supported by my work setting	30	12.0%
Lack of familiarity with the intervention	13	5.2%
There are no barriers	12	4.8%
Other (please specify) ^a	10	4.0%
Privacy concerns	2	0.8%
Questions about benefit	2	0.8%

^a Responses included "not offered yet" (2), "cultural concerns" (1), "was not allowed" (1), "low demand" (1), "not relevant" (1), "not payable by insurance" (1), "provided by another music therapist" (1), "patient died" (1), and "questions about needed equipment" (1).

Current Practice of Heartbeat Recording Projects in Music Therapy

The data reported in the following section were gathered from the portion of the survey open to respondents with experience using heartbeat recordings and reflect this

population. This section will include the remaining portions of the survey, including which music therapists use heartbeat recordings, settings and populations where heartbeat recordings are being used, how music therapists learn to create heartbeat recording projects, clinical aspects of heartbeat recording projects, and technology used for heartbeat recording projects. Some of these questions allowed for multiple response selections.

Settings and Populations Where Heartbeat Recording Projects are Being Used

Respondents were asked about the settings in which they have used heartbeat recordings projects. The most common location was children’s medical hospitals, followed by hospice and palliative organizations (see Table 4). The categories “neonatal intensive care unit” and “private practice” were added to reflect responses entered via text. Responses that referred to specific areas of hospice and palliative work, such as perinatal or pediatric hospice, were categorized as “hospice and palliative organization.”

Table 4

Settings Where Heartbeat Recording Projects Are Being Used

Setting	Frequency	Percentage
Children's medical hospital	132	68.0%
Hospice and palliative organization	67	34.5%
Adult medical hospital	40	20.6%
Hospice in-patient center	25	12.9%
Skilled nursing facility or senior care home	11	5.7%
Neonatal intensive care unit	4	2.1%
Other (please specify) ^a	4	2.1%
Private Practice	3	1.5%

^a Responses included outpatient/inpatient oncology (1), pediatric skilled nursing facility (1), palliative care unit of adult hospital (1), and mental health hospital (1)

While individuals with terminal illness or who were actively dying were the most common population with whom respondents used heartbeat recordings, respondents also indicated that heartbeat recordings were being used with individuals without serious illness

(see Table 5). Responses mentioning specific serious illnesses were categorized as “individuals with serious illness.” Text responses indicated other populations, including transplant patients, pediatric intensive care unit (PICU) patients and neonatal intensive care unit (NICU) patients, pregnant mothers, families, and anyone for whom the intervention is clinically relevant. Categories were added to reflect these responses.

Table 5

Populations With Whom Heartbeat Recording Projects Are Being Used

Setting	Frequency	Percentage
Individuals with terminal illness	168	87.0%
Individuals who are actively dying	158	81.9%
Individuals with serious illness	110	57.0%
Individuals without serious illness	37	19.2%
Transplant patients	5	2.6%
PICU/NICU patients and families	4	2.1%
All, as clinically relevant	4	2.1%
Pregnant mothers	2	1.0%
Families of patients	2	1.0%

Learning to Create Heartbeat Recording Projects

Most respondents indicated that they had learned to record heartbeats from a music therapist colleague/supervisor (see Table 6). Additional categories were created to reflect responses entered via text, including “trial and error” and “stethoscope manufacturer.” Responses mentioning a specific music therapist were categorized as “I learned from a music therapist colleague/supervisor.” Three responses in the “other” category did not seem to address the question of learning to record a heartbeat and indicated that the question might have been misunderstood.

Table 6*Methods of Learning to Take a Recording of a Person's Heartbeat*

Method	Frequency	Percentage
I learned from a music therapist colleague/supervisor	160	82.5%
I learned from informal resources, i.e., YouTube, Google	50	25.8%
I learned from a workshop, training, or CMTE	40	20.6%
I learned from a medical professional, i.e., nurse, doctor	24	12.4%
I learned from scholarly work(s), i.e., journal articles, books	16	8.2%
Trial and error	15	7.7%
Other (please specify) ^a	5	2.6%
Stethoscope manufacturer	3	1.5%

^a Responses included “elementary school” (1), “cannot recall” (1). Additional responses (3) suggested that this question might have been misunderstood by some respondents.

Learning from a music therapist colleague/supervisor was also the most common method of learning to create a heartbeat recording project (see Table 7). The categories “trial and error” and “previous training in production” were added to reflect responses entered via text. Responses mentioning specific music therapists were added to the category “I learned from a music therapist colleague/supervisor.” Informal resources, along with workshops, trainings and CMTEs, were also common methods of learning. It is notable that some respondents referred back to their previous training in production to assist them in creating heartbeat recordings.

Table 7*Methods of Learning to Create a Heartbeat Recording Project*

Method	Frequency	Percentage
I learned from a music therapist colleague/supervisor	150	77.3%
I learned from informal resources, i.e., YouTube, Google	51	26.3%
I learned from a workshop, training, or CMTE	44	22.7%
Trial and error	30	15.5%
I learned from scholarly work(s), i.e., journal articles, books	14	7.2%
Previous training in production	9	4.6%
Other (please specify) ^a	3	1.5%

^a Responses included “IT department” (1), “hospitality team” (1), and “Apple store course: (1).

When asked which method of learning to create heartbeat recording projects was most helpful, the majority of respondents selected “music therapist colleague or supervisor” (see Table 8). Categories were added to reflect responses entered via text including “trial and error” and “previous training in production.” Responses mentioning a specific music therapist were categorized as “music therapist colleague/supervisor.” It is notable that no respondents selected scholarly work as the most helpful method of learning. This question did not offer text responses, so there may be additional helpful methods of learning that were not reported.

Table 8*Most Helpful Methods of Learning to Create a Heartbeat Recording Project*

Method	Frequency	Percentage
Music therapist colleague/supervisor	115	61.2%
Not applicable/I only learned from a single source	47	25.0%
Workshop, training, or CMTE	15	8.0%
Informal resources, i.e., YouTube, Google	13	6.9%
Scholarly work(s), i.e., journal articles, books	0	0.0%

Clinical Aspects of Heartbeat Recording Projects

There was a great deal of variety in responses to questions about clinical aspects of heartbeat recording projects. The majority of respondents created heartbeat recordings only occasionally throughout the year, while some respondents reported creating heartbeat recording projects once or more per week (see Table 9). Respondents differed regarding when they offered heartbeat recording projects as an intervention. The categories “it depends,” “preferably once rapport is built,” “upon referral or request,” and “at imminent death” were created to group responses to this question entered via text. The majority of respondents reported that they offered heartbeat recordings “once rapport has been established” ($n = 62, 34.3\%$), followed by a number of respondents reporting that “it depends” ($n = 55, 30.4\%$). Some respondents offered this intervention “during the initial visit” ($n = 18, 9.9\%$), while others offered it “only after significant clinical work has been done” ($n = 13, 7.2\%$). A number of respondents indicated a preference for building rapport first by specifying that they offered it “preferably once rapport is built” ($n = 13, 7.2\%$), while others indicated that they offered the intervention “upon referral or request” ($n = 9, 5.0\%$) or “at imminent death” ($n = 9, 5.0\%$). Other responses ($n = 2, 1.1\%$) included one respondent who only used heartbeat recordings once and another who used heartbeat recordings with teens or children to “connect to their body.” Two responses sorted into “at imminent death” noted that all patients at the facility at end-of-life were offered this intervention. One respondent introduced a possible clinical dilemma when stating, “Some patients want the recording but no music therapy.”

Table 9*Frequency of Creating Heartbeat Recording Projects*

Frequency	Frequency	Percentage
Somewhat infrequently (occasionally throughout the year)	75	38.7%
Somewhat frequently (several times per month)	62	32.0%
Very infrequently (less than a few times per year)	33	17.0%
Very frequently (once per week or more)	24	12.4%

The most common combination for a heartbeat recording project was heartbeat and recorded music (see Table 10), although all other combinations surveyed were also represented, and a number of other ideas were listed as well. The categories “it depends” and “heartbeat and voice” were created to reflect responses entered via text. Responses sorted into “heartbeat and voice” included responses such as “audio clips of the patient laughing,” “heartbeat and family/patient speaking or reading a story,” and “patient’s voice speaking special message to family.” As with the question about when the intervention is offered, a number of respondents reported that “it depends.”

Table 10*What is Included in a Heartbeat Recording Project?*

Item	Frequency	Percentage
Heartbeat and recreated music performed by music therapist	161	87.0%
Heartbeat alone	129	69.7%
Heartbeat and original song performed by music therapist	81	43.8%
Heartbeat and recreated music performed by patient/family	71	38.4%
Heartbeat and pre-recorded music	69	37.3%
Heartbeat and original song performed by patient/family	60	32.4%
It depends	10	5.4%
Heartbeat and voice	9	4.9%
Other (please specify) ^a	3	1.6%

^a Responses included “printout of heartbeat sound waves” (1), “sound collages, build-a-bears, and print-outs of heartbeat” (1), and “only created once” (1)

When asked about what portion of the project was completed during the music therapy session, 97.8% ($n = 181$) reported that they recorded the heartbeat, 86% ($n = 159$) reported that they selected the songs, 37.8% ($n = 70$) reported that they delivered the completed project, 21.1% ($n = 39$) reported that they recorded the music, and 3.2% ($n = 6$) reported that they mixed the audio. See Table 11 for what information is typically gathered from the patient and family during the music therapy session. Two categories were created to reflect responses entered via text: “it depends” and “family/patient vision for the project.” Two responses were relevant to the topic of privacy and copyright, including “signed consent form” and “available music selections are limited to public domain material (or songs written by patients, caregivers, or staff).”

Table 11

Information Gathered from Patient and Family

Information	Frequency	Percentage
Meaningful song choices	169	91.4%
Stylistic music preferences	125	67.6%
Family's thoughts about the patient	97	52.4%
Patient's messages for family	73	39.5%
Important people in the patient's life	73	39.5%
It depends	9	4.9%
Other (please specify) ^a	7	3.8%
Family/patient vision for the project	2	1.1%
None	2	1.1%

^a Responses included “signed consent form” (1), “client’s vocalization” (1), “song of kin” (1), “staff messages for patient” (1), “spiritual/cultural preferences” (1), “word associations” (1), and “public domain music selection” (1)

Respondents adjusted various elements of the recording. The most common element to adjust was the volume of the heartbeat ($n = 177, 96.2\%$), followed by the sound of the heartbeat ($n = 110, 59.8\%$), length of the prerecorded music ($n = 68, 37.0\%$), tempo of prerecorded music ($n = 61, 33.2\%$), and tempo of the heartbeat ($n = 38, 20.7\%$). Categories

were created to reflect other approaches to editing which respondents reported via text, including “reducing noise” ($n = 11, 6.0\%$), “looping the heartbeat” ($n = 5, 2.7\%$), “minimal to no editing of the heartbeat for integrity” ($n = 5, 2.7\%$), “boosting bass” ($n = 2, 1.1\%$), “equalizing” ($n = 2, 1.1\%$), “depends on client” ($n = 2, 1.1\%$), and “tempo of original music” ($n = 1, 0.5\%$). Answers categorized into “minimal to no editing of the heartbeat for integrity” included statements such as, “I try to uphold the heartbeat integrity as much as possible” and “Keep [the heartbeat] as authentic as possible and modify music around it.”

The majority of respondents reported that once the heartbeat recording project is delivered, they do not communicate further about the project with the patient or family (see Table 12). Two categories were created for similar responses that were entered via text, including “it depends” and “follow-up initiated by patient.” Of the responses categorized as “initiated by patient,” several respondents noted that they would provide their contact information with delivery of the project.

Table 12

Communication Following Delivery of Project

Communication	Frequency	Percentage
I do not communicate further about the project with the patient/caregiver once it has been delivered	65	36.9%
I follow up with the patient/caregiver once to discuss/process the project	51	29.0%
It depends	23	13.1%
I follow up with the patient/caregiver multiple times to discuss/process the project	18	10.2%
Follow-up initiated by patient	16	9.1%
Other (please specify)	3	1.7%

^a Responses included “project was not delivered” (2), and “no opportunity for follow-up” (1).

Respondents reported delivering completed heartbeat recording projects in a variety of formats. Additional categories “it depends” and “stuffed bear and CD/audio file/thumb

drive” were created to reflect similar responses reported via text. The majority of respondents reported delivering completed projects by emailed audio file ($n = 69$, 38.8%), followed closely by responses stating that “it depends” ($n = 40$, 22.5%). Additional responses included hand-delivered CD or thumb drive ($n = 30$, 16.9%), mailed CD or thumb drive ($n = 26$, 14.6%), stuffed bear and CD/audio file/thumb drive ($n = 7$, 3.9%), and text entries from the “other” category ($n = 5$, 2.8%) including “air drop” (1), “SoundCloud with QR code” (1), “WeTransfer” (1), “unlisted YouTube link” (1), and “thumb drive in hand-painted box” (1).

Equipment Used for Heartbeat Recording Projects

The most commonly used stethoscope was a lapel mic with a stethoscope, followed by the Thinklabs digital stethoscope and the Eko digital stethoscope (see Table 13). Respondents identified a number of additional stethoscopes used for recording heartbeats and appropriate categories were created for these responses. Responses that mentioned using a stethoscope with a microphone were sorted into “lapel mic with stethoscope.” Two respondents who could not remember what kind of stethoscope they used were sorted into the category “do not remember.”

Table 13*Stethoscopes Used for Heartbeat Recordings*

Stethoscope	Frequency	Percentage
Lapel mic with stethoscope	59	33.3%
Thinklabs digital stethoscope	53	29.9%
Eko digital stethoscope	41	23.2%
Littman digital stethoscope	12	6.8%
Steth IO	2	1.1%
Paramed	2	1.1%
Other microphone or recording device	2	1.1%
Do not remember	2	1.1%
Doppler/Ultrasound	2	1.1%
Thinklabs or Wombmusic	1	0.6%
Thinklabs or lapel mic	1	0.6%

Half of respondents reported that they had only used one stethoscope. Of those who had used multiple, the majority reported that they preferred the Eko digital stethoscope, followed by the Thinklabs digital stethoscope, and finally the lapel mic with stethoscope (see Table 14). Several respondents reported two stethoscopes as their preferred choice, which may suggest that it depends on the clinical situation or that there are certain aspects that are preferred in each stethoscope. One respondent noted that the Thinklabs digital stethoscope “has multiple settings for frequency capture,” while another stated, “I prefer the sound quality of the Thinklab [*sic.*] but find that the lapel mic is more user friendly.”

Table 14*Preferred Stethoscope for Heartbeat Recording*

Stethoscope	Frequency	Percentage
Only used one stethoscope	87	52.1%
Eko digital stethoscope	28	16.8%
Thinklabs digital stethoscope	25	15.0%
Lapel mic with stethoscope	17	10.2%
Littman digital stethoscope	2	1.2%
Thinklabs and womb music	1	0.6%
Thinklabs and lapel mic	1	0.6%
Ultrasound or echo	1	0.6%
StethIO or Doppler	1	0.6%
Thinklabs or Wombmusic	1	0.6%
Condenser mic, ultrasound, and stethoscope attachment	1	0.6%
Lapel mic or infant monitoring mic with stethoscope	1	0.6%
Eko digital stethoscope, lapel mic, or regular mic with Doppler	1	0.6%

The majority of respondents used GarageBand as the digital audio workstation (DAW) to create heartbeat recording projects, followed by LogicPro and Audacity (see Table 15). Categories were created to reflect other responses entered via text, including “Garageband combined with another DAW,” “ProTools,” “Ableton Live,” “Reaper,” “CuBase,” “Digital Performer,” and “Luna.” A Mac computer or laptop was the most common device used to create the project ($n = 152$, 84.9%), followed by an iPad or other tablet ($n = 87$, 48.6%), a Windows computer or laptop ($n = 15$, 8.4%), an iPhone or other smartphone ($n = 12$, 6.7%), and other ($n = 7$, 3.9%). Other responses include “record on iPad/tablet and edit on laptop” (2), “prefer computer over iPad” (2), “mainly laptop” (1), “Zoom H2n” (1), and “iPod touch” (1).

Table 15*Digital Audio Workstations Used for Heartbeat Recording Projects*

DAW	Frequency	Percentage
GarageBand	133	75.6%
LogicPro	15	8.5%
Audacity	12	6.8%
GarageBand combined with another DAW ^a	7	4.0%
Pro Tools	3	1.7%
Ableton Live	2	1.1%
Reaper	1	0.6%
CuBase	1	0.6%
Digital Performer	1	0.6%
Luna	1	0.6%

^a DAWs listed as being used in combination with GarageBand include Logic (3), Audacity (2), Pro Tools (1), and Ableton Live and Audacity (1).

Interview

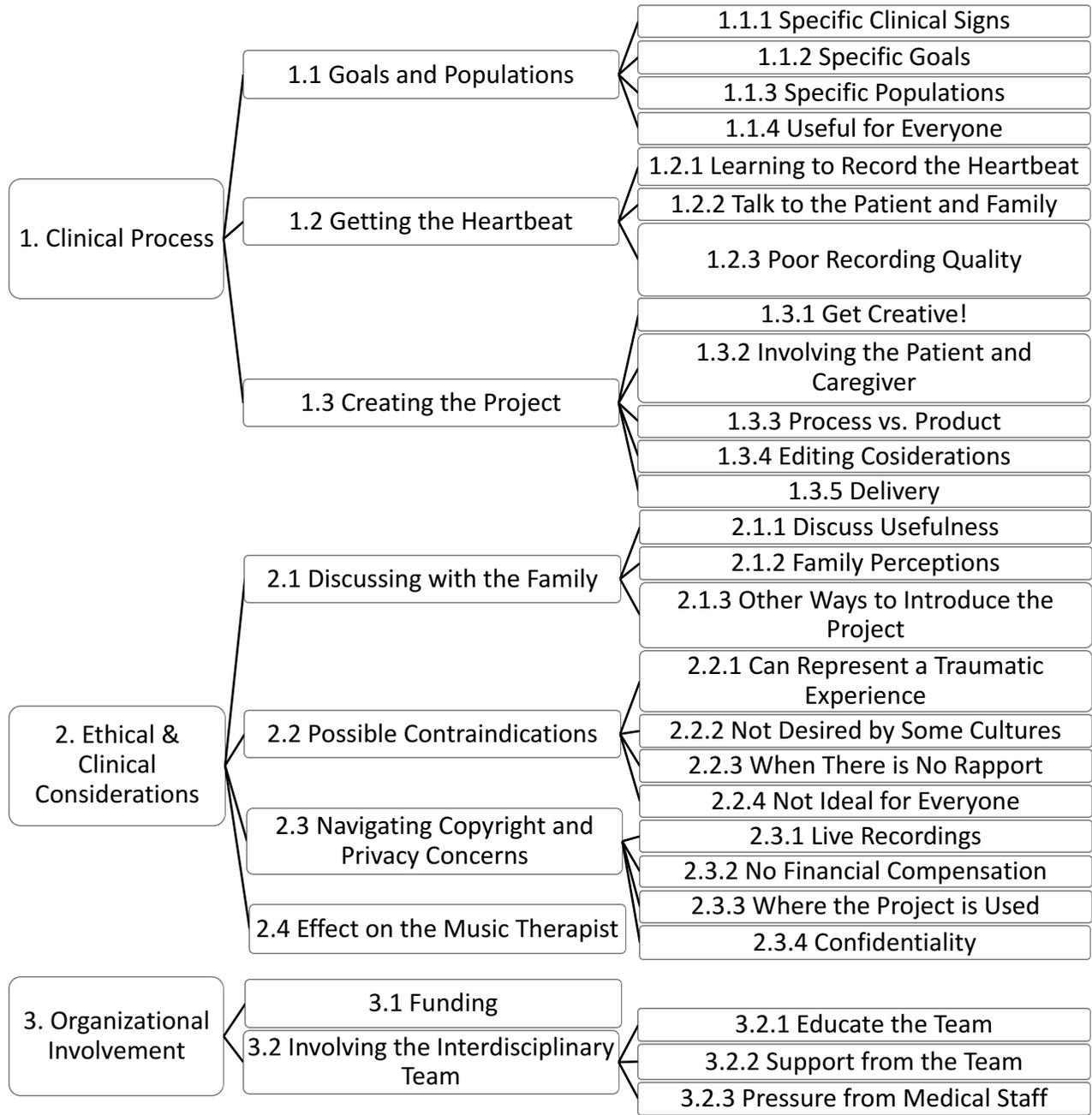
The survey concluded by inviting respondents with at least one year of experience with heartbeat recordings to indicate whether they would be interested in participating in a follow-up interview and to provide their name and email address if so. Of the 163 respondents to this question, 62% ($n = 101$) indicated that they qualified and would be interested, while 38% ($n = 62$) of respondents indicated that they either were not interested or did not meet the eligibility requirements. All respondents who indicated that they were interested provided their contact information.

Chapter 5: Interview Results

This chapter reports the results of a thematic analysis of three interviews conducted with board certified music therapists who indicated on the survey that they would be willing to participate in a follow-up interview. At the time of the interview, each informant had at least one year of experience with heartbeat recordings in music therapy. The themes and subthemes resulting from the thematic analysis have been sorted into three content areas: The Clinical Process, Ethical and Clinical Considerations, and Organizational Involvement. Themes and subthemes can be seen in Figure 3.

Figure 3

Content Areas, Themes, and Subthemes from Interview Data



Informant Selection Process

One informant was purposely selected because his name was mentioned by survey respondents as someone knowledgeable about heartbeat recordings, as he pioneered the intervention. Other participants who volunteered for the interview were sorted into two categories, medical and hospice/older adults, based on their experience with each population. A random number generator was then used to select one volunteer from each category. There was some crossover on these two lists due to respondents having experience with multiple populations. All three informants who were selected agreed to participate in the interview. Two informants were given pseudonyms to maintain anonymity. The third informant, Brian Schreck, chose to have his name disclosed.

Informant Characteristics

Informants included two music therapists who identified as female and were in the 20-29 age bracket, and one who identified as male and was in the 40-49 age bracket. All informants identified as White and reported having at least two years of experience with heartbeat recordings. Informants indicated that they had used heartbeat recordings in either the Southeastern or Great Lakes regions of AMTA and in settings including children's medical hospital, adult medical hospital, hospice and palliative organization, hospice inpatient center, skilled nursing facility or senior care home, and perinatal hospice. One informant had a bachelor's degree in music therapy, one had a master's degree in music therapy, and one had a master's degree in a related field.

Content Area 1: The Clinical Process

Theme 1.1: Goals and Populations. The informants noted the wide variety of clinical situations in which heartbeat recordings might be used. Some of these were related to clinical

signs that point to the intervention's potential efficacy. The informants also described using heartbeat recordings to target specific goals and identified trends in particular populations where this intervention may be used.

Sub-theme 1.1.1: Specific Clinical Signs. A patient or family's strong connection to music or music therapy or their history of using music as a coping tool were considered clinical signs that this intervention might be appropriate for the client. Anne spoke of the importance of considering the role of music in the lives of the patient and the people surrounding the patient, but she also noted the importance of building a therapeutic relationship prior to offering the intervention.

It's a really good project for someone who's musical, if the patient is a very musical person and that's how their family remembers them. I also think it's beneficial if the family, spouse, friends, or whoever's around the patient uses music to cope with things already, and if music therapy has been a part of their process throughout their time in the hospital or they've had that relationship.

Julie found that the recordings can be helpful in situations where a family cannot be present, and she also acknowledged a relationship with music to be a factor.

If a child is here and the family lives far away and has other children at home and can't be here, we would send their recording to them, something that they can listen to since the family members can't be here. So, someone with family that wants to listen to that. For someone who is motivated by music, it's great to have music attached to the recording.

Sub-theme 1.1.2: Specific Goals. Informants shared that they have used this intervention for a variety of goals. Legacy work was reported to be the most common goal,

and Brian referred to the possibility of using heartbeat recordings as “a support system in this ongoing treatment of grief” and “with patients who in any way are having trouble speaking, as a different way that they could tell their family that they love them.” Julie shared an example of using a heartbeat recording as legacy work for a family of a child with a poor prognosis in which the musical improvisations of the child and family were mixed together with the heartbeat recordings of the child, father, and mother.

While legacy work may be the most common goal of heartbeat recordings, other goals were reported as well. Brian shared that he has used this intervention with patients to connect to their internal rhythms.

People will say, “I have no rhythm.” I like to say, “Well, yes, you do. Let's talk about that. What you mean?” We can even Bluetooth the Thinklabs into an external speaker and have that out loud in the session, and then they can just be holding their own heartbeat outside of themselves, and then music can be created around that as a way to connect.

Julie reported using a heartbeat recording to commemorate a child's length of stay in the hospital. She also spoke about using a heartbeat recording to replace the memory of a traumatic sound which occurred during childbirth.

Sub-theme 1.1.3: Specific Populations. Informants discussed using heartbeat recordings with a variety of populations. Brian shared that “a lot of this work started in intensive care ... [with] infants in the NICU, the CICU, and the [PICU]” and noted that he had since used heartbeat recordings in perinatal hospice with parents of babies who were not expected to survive. He stated, “Sometimes that was the only sound of life that we were able to capture and then use in whatever way that they wanted to.”

Anne and Julie have both used the intervention for transplant patients. Julie reported that she would blend the sounds of the native heart into the sounds of the transplanted heart. This was usually done with the transplant recipient, and both Julie and Anne reported patients desiring to send recordings back to the donor's family. Anne described her work with a patient who received a lung transplant and wanted to create something for the donor's mother. This patient sang a song using the transplanted lungs and sent the recording of the song mixed with her heartbeat to the donor's mother.

Julie reported using heartbeat recordings for patients with eating disorders. She stated, "The recordings were done with each member of the group, and then they also recorded a song about what made their respective hearts beat, or their reasons to recover."

Sub-theme 1.1.4: Useful for Everyone. All informants felt that it was possible to use heartbeat recordings as an intervention for anyone. Brian noted the variety of possible uses of the recording when he said that it "could be used in some sort of recording project with anyone." Anne and Julie made similar statements, and Julie noted that her team offers the intervention to "almost all of the end-of-life patients."

Theme 1.2: Getting the Heartbeat

Informants said that the process of getting the heartbeat can have a steep learning curve, that the stethoscope matters, and that there are situations in which it is hard to get a good quality recording. They also reported that a conversation with the patient or family before taking the heartbeat can be helpful.

Sub-theme 1.2.1: Learning How to Record the Heartbeat. Julie shared that her team initially had trouble getting quality recordings but were able to get help from the Apple store.

We actually took a class at the Apple store with an Apple genius telling us how to use GarageBand in the best way and how to get the best recording. That solved a lot of our issues with why we were recording the room sound instead of through the stethoscope. So that was really helpful. (*Interviewer: So, it was about using the right input?*) Right, and the order of operations in which everything was plugged in seemed to be really crucial, and we had a hard time figuring that out on our own. That was something that Apple helped us out with. We also learned that having the volume down almost to the lowest is the best way to get a good heartbeat recording.

Otherwise, it was crunchy or maxed out.

Anne shared that she, too, had trouble getting a heartbeat recording at first because there “wasn't a ton telling us exactly how to do it,” but that she eventually found support from the nursing staff. Julie advised music therapists to “practice on yourself and on your coworkers before you're in the stressful situation with the family that is in distress.” Like Ann, Julie advocated for reaching out to the nursing staff for help.

The nursing staff was really helpful with that, even asking them, “Hey, I am a musician, can you help me find where's the best place to find the heartbeat?” They'll usually say yes. They can also be helpful with turning tones on machines off during the two minutes that you need to record.

Sub-theme 1.2.2: Talk to the Patient and Family Before. Informants reported that it can be helpful to talk to the family and patient before getting the heartbeat recording both so they can know what to expect and so they can give consent. Julie usually would ask families for permission and remind families that they can stop at any time.

We do obviously ask permission from families. We don't just go in and do it. ... I usually tell the family that it can be an emotional process so we can stop at any time. I've actually never had a family tell me "I can't do this right now" or anything, but I like to give them that option.

Brian also encouraged other music therapists to ask permission, explain what will happen, and ask if the patient would prefer that a family member or nurse place the stethoscope. Anne commented that being unable to find the heartbeat immediately might be alarming for families, and she recommended giving them a warning that it may take a few tries.

At the beginning, there were a couple of times when we couldn't find the heartbeat. ... What I would normally do is say, "I'll be able to find something. I'll be able to get this, but if I'm looking around for different things don't be alarmed." A lot of times, they'll think, "Is their heart still beating?" and they're really anxious because they see me over there finicking around. It is really key to talk to the families about what it looks like to get the heartbeat.

Sub-theme 1.2.3: Poor Recording Quality. Informants encountered several situations where a recording of the heartbeat was hard to get. In particular, Julie and Brian found that loud medical equipment could make this challenging. Brian reported difficulty finding a heartbeat "in severe intensive care where there are tons of machines and ECMO and all these other things."

Physical aspects can also affect quality of the recording. Sometimes, a person's weight might be a contributing factor to the sound of a heartbeat. Brian noted that "the larger a person is, the more difficult it is to get a clean, loud heartbeat, unless you are using something that has an amplified capacity like Thinklabs which you can turn up quite a bit,

almost times 10.” Anne found that respiratory sounds can cause problems. She stated, “The most difficult thing people run into is that when [the patient is] actively dying they have that really rapid breathing or really coarse breath sounds, and you can only get like one beat in between.”

Informants reported navigating these difficulties in a few ways. Brian advocated for getting the recording earlier when possible, stating, “I think that the earlier we can do this it's always better, because I think that even a layperson can tell when it doesn't sound quite right.” Both Anne and Julie pointed out that just one heartbeat was often enough to use for the project. Julie stated, “Something that I ended up learning a lot was that if I could just get one or two beats, I would loop it and it would be okay.”

Theme 1.3: Creating the Project

The clinical process of creating the project with the patient and family and editing the final result is complex to navigate. Aspects of the process to consider include how much one involves the patient and family in the creation, how important the process of creating the project is, and how much to edit the heartbeat.

Sub-theme 1.3.1: Get Creative! All informants saw creativity as a part of using heartbeat recordings in music therapy. Julie advised music therapists, “I would say: be really creative.” Anne gave an example of creatively using the patient’s voice at the beginning of the recording to share a personal message like “I love you.” When discussing methods of delivery, Brian acknowledged that “the sky is the limit to how creative people are with [ways to deliver the finished product],” but he encouraged music therapists to have “a specific conversation ... [with] the recipients about how they will best be able to access it.”

Sub-theme 1.3.2: Involving the Patient and Caregiver. Julie and Brian both described ways of inviting the patient and family into the process of creating the project. Julie shared that she often gives the family a chance to listen to the heartbeat.

Usually, if it's not a time sensitive thing, I do like to make it an intervention for the entire family. I tell them, "I'm going to find the heartbeat first, and then I can pass the headphones to you if you would like to listen to it." I'll find the heartbeat, I'll record eight bars or so if I feel like that's good, and then I'll have the family listen to the heartbeat as well, and they can pass the headphones around the room.

While Julie noted that editing is usually "done outside the session," Brian shared that he likes to involve the patient in the entire process.

If we can get that heartbeat and then a song is chosen, we can get that together slowly, not feeling like it's all the music therapists doing this alone in their office. To me, this is a process-based intervention that they should be as involved in as possible, even in how the heartbeat sounds itself. ... [Even in one-time sessions], it still doesn't need to be a great deal of time by the therapist in their office. Some of it can be done in the room, so that there's a participation, even if it's just by actively listening. The more involved they are in this process, including giving them the invitation to hold the stethoscope on their loved one, will help them remember.

Brian also described some ideas about how to involve the patient in the recording.

That takes it up a notch in my mind, even having the chance to say, "I love you," their actual words, or even a funny memory. They can say, "I want you to listen to this when you're in the shower every day," or some quirky thing like, "When you're walking our dog, this is our song." You can just pretend they're right there with you.

If there's even some guidance and description from the actual patient about who they're leaving this to or who this message is for, that takes it up a notch, too. The more involved they are, the more “everything” it is.

Sub-theme 1.3.3: Process vs. Product. There was some variety in how much clinical emphasis informants placed on the “process” aspect of creating a heartbeat recording project, including the various media that might be a part of it, versus the “product” of the end result. There was also variety in how much time a music therapist might have with a client to create the project, which could influence what the process looks like.

Both Brian and Anne felt that sometimes heartbeat recording projects could help warm people up to the idea of music therapy. Brian said, “I think it's an excellent way to engage someone that is a little bit skeptical about music therapy.” Anne also experienced heartbeat recordings as a way to introduce music therapy to people, and she noted that it can increase music therapists’ access to some patients.

It opened the door to a lot of patients who the nurses would have otherwise thought, “Oh, they don't need music therapy, they’re about to die.” You know, that’s a time when we could really help, when it would be very beneficial.

For various reasons, time with patients can be limited when music therapists offer this intervention. Brian shared that when time is short, music therapists “can be experts in quickly building rapport and going far quickly with patients and families.” Julie noted that she places the focus more on the product than the process of creating the intervention in these instances.

I don't think that we have a lot of those: “They're dying right now. Hurry.” So, I don't have a ton of experience with that, but the ones that I do, I make it more about the product that they receive afterwards, and less about the intervention itself.

Brian also commented on how a short version of a project can end up being useful.

Having a short version is good, something that's easily accessible even on your phone, something that you could text to people and it's not a 5-minute-long recording.

I've found that people might just need a little 90 seconds just to think, "All right. I feel connected. I feel okay now. I'm going to go about the rest of my day."

Sometimes, only a recording of the heartbeat is needed or desired. Julie reported that in situations where this is requested because a patient is close to death, "They are a higher priority ..., because it could be time-sensitive." Brian added that he might not even discuss the possibility of adding music if the heartbeat is all that is wanted. Anne felt that sometimes it was best to just use the recording of the heartbeat alone to give the family more time and space for grieving privately.

Sometimes, I think that really was the best thing for the families. Sometimes it was the situation where they didn't really want a new person in there and they had a lot of family who were actively grieving. Those are situations that we would walk into a lot of times, but when the family is already on edge, I was slow and hesitant to push anything. I was happy to do whatever level of music therapy they wanted, and the heartbeat project was just one level of it.

All informants did place an emphasis on a process-based approach being very important and usually preferred. Julie stated, "The long-term intervention with the family is great." Anne spoke to the importance of the process and pointed out that even if the music therapist is only able to get a quick recording, it is possible follow-up about it later.

If I'm pressed for time, it's the first time meeting the family, and the patient's about to die, I will go on and record the heartbeat right then and try to have the process happen

later. The process needs to be there regardless. I do think that it's possible to happen after the product has been given, rather than always just before.

Brian referred back to the importance of bringing the families into the process, saying, "To me, this is a process-based intervention that [the family] should be as involved as possible in, even in how the heartbeat sounds itself." He also acknowledged that a focus on process can lead to an unfinished product, which can also carry meaning for the patient or family.

To me, if it's unfinished a little bit, it does give room for ongoing communication that they're also participating in where it should go and if it's done or not. In my opinion, this work is never quite done, and that's okay because grief is never done.

Sub-theme 1.3.4: Editing Considerations. When editing together the heartbeat with any additional media, a number of audio factors can be adjusted, such as tempo, volume, sound, and equalization. Informants shared that they consider the sound and authenticity of the heartbeat as well as where the recording might be played when determining what to adjust. Anne reported rarely changing the tempo or sound of the heartbeat and, in cases where editing was necessary, aiming for authenticity.

If it's in 3/4 or 6/8, I'll do three beats and loop it, or I'll do four beats otherwise. If I can only get one beat at a time, that's where the tempo might actually change, because when I'm looping that, it depends on the space around it. That is the only time. I wouldn't purposely change the tempo or anything, but that might alter it a little bit. I would try to get as close as possible to the actual to the actual rhythm. When we did babies, it was a lot different because we would have a whole lot of beats in one. So, the biggest thing I did with editing was make sure to amplify the bass sounds to make

it a little more boomy. I did change the timbre of it, but it just made it sound more like the actual heartbeat.

Brian said that he is careful to discuss with the patient or family how the recording will be used, and he tries to take this conversation into consideration when editing the heartbeat.

Have in mind whether they are only going to be listening to it on their phone. If so, you might want to do it a little bit more treble-y sounding so that anyone can hear it, no matter what. If it's going to be on a huge awesome stereo system in their car and at home, let's crank up the bass super loud so that they can feel it moving against them. These are things that you can talk about and ask, "How do you wish to have this?"

Sub-theme 1.3.5: Delivery. There are various creative ways to deliver heartbeat recording projects. Anne shared that her team uses CDs and mp3 files, while Julie reported that her team uses thumb drives. Julie and Brian pointed out that families may not have ways to utilize all formats. Julie reported, "We have done CDs but we've found that a lot of families don't have a way to play CDs anymore." Brian spoke to the importance of having this conversation with family to determine the best format.

If they are flip phone people that have a CD player at home, then it's going to be CD. If they don't have any CDs or they stream everything then an email is fine. We can put it on a thumb drive. I know that some people have done them in protected SoundCloud, where you have to have a password to get into and then it's theirs to keep. You could also do a QR code. It depends on how techie you are and how much you want to be involved in this, but there are safe ways to get it to everyone. It's still very individualistic.

Content Area 2: Ethical & Clinical Considerations

There are several clinical and ethical considerations music therapists might make before offering a heartbeat recording as an intervention, including how to discuss the project with the family, possible situations where it might be contraindicated, privacy and copyright issues, and the effect on the music therapist.

Theme 2.1: Discussing with the Family

When discussing heartbeat recording projects with families, it may be important to talk about how they will use it. Families may also have perceptions about what the heartbeat recording can represent, which can lead to difficult conversations. There are multiple ways to introduce how a heartbeat recording project might be used.

Sub-theme 2.1.1: Discuss Usefulness. Brian shared that it is important to have a conversation with families about how they plan to use the heartbeat recording.

The most important part about this intervention is really getting to the bottom of how it's useful and why it would be useful with an exact family. Everyone's going to be different, and how much stuff you put into it and why you've put it in there really depends on your relationship with them and how much they want to go into it. He also shared an example of what might happen if potential uses are not discussed in the session.

I didn't really think about this until we gave [a teddy bear with a heartbeat recording] to one of my cousins. It was her mom leaving a message to both of the grandkids, so her kids had two stuffed animals at home, and she was hearing her mom in the house saying how much she loved these two like 45,000 times a day. It ripped her heart out, and then it became something that was annoying. It was super meaningful on the first

day, but a month later she wanted to hide them from her kids so that she didn't have to hear it all the time. I think just be careful in getting feedback, refining these things, and understanding how it is actually used out in the real world. Some of that needs to be discussed and described when you're doing it, even the parameters of, "You never have to listen to this, but just in case you might want to one day, it'll be there for you."

Sub-theme 2.1.2: Family Perceptions. Even when families are not aware of what exactly a heartbeat recording is in the context of music therapy, it is often associated with death in some way. Brian shared that this is a strong possibility in oncology work.

It could open up a conversation. For instance, I work in oncology now with adults, where we kind of push death away a lot. If someone may connect the dots or they've heard about this, they may say, "Are you trying to do this because you're telling me that I'm at the end of my life?"

Anne felt that there may be situations in which this perception of heartbeat recording projects could present an ethical dilemma. She said, "I think that's where at least there's a gray area, an ethical line, because there is a chance that it could just do more harm in the sense of, 'Why are you giving me this really sad thing?'" She reported that this often is a hard discussion to have, and that people might not be ready for it.

There was never a time where I thought that I caused harm, but there were times where it was a very tough discussion to have to explain, "This is not a decision really you have to make right now, but if it's okay with you I want to just press record on the stethoscope, hold this recording, and months from now, I'm going to reach out to you and maybe we'll talk about this." But that discussion only came after they would

say, “Who are you? Get out of here. No, I don't want to do anything. We just want family.” It made for more difficult situations, but the project proved beneficial to them (per their report) later on in their grieving process.

Brian observed that because of this perception of the intervention, “it does take a little bit of courage from the therapist to even offer it.”

Sub-theme 2.1.3: Other Ways to Introduce the Project. Two informants shared that they sometimes introduce the project in indirect ways, given the associations some people have with heartbeat recordings and the various ways they are being used in practice. Julie might offer a heartbeat recording as “something that we can provide to [the] family that can't be here” or “This is just something we offer to families.” Brian reported that he tends to talk to families about heartbeat recordings as a source of connection, such as,

“This is a different way that you could say ‘I love you’ to anyone that's not around right now and a different way we can feel connected.” I usually use language like “connection” and “bond.” To me there's always a way that we can let our loved ones know that we love them, and this is just another vehicle for it.

Theme 2.2: Possible Contraindications

Informants identified a few situations in which heartbeat recordings might not be indicated, or might be contraindicated, for a particular patient and family. These include when the heartbeat could represent a traumatic time or experience, when the heartbeat recording might not be desired for cultural reasons, and when there is no rapport. Ultimately, informants encouraged music therapists to remember that this intervention is not ideal for everyone.

Sub-theme 2.2.1: Can Represent a Traumatic Experience. Sometimes, a heartbeat recording can represent a difficult time for families. Brian felt that this could happen in intensive care and urged music therapists to consider carefully whether a representation of that difficult time is the right choice.

A lot of the recordings I started doing in the first place were to preserve good memories, and most memories in intensive care you would not want to come back to.

I think be careful with that. Is this something that we want to cement in time?

Julie posed a similar question, stating, “On a cardiovascular unit, do they want a recording of this ‘bad heart’?” Anne similarly felt hesitant about offering heartbeat recordings in settings where there was acute trauma but stated that it might be more appropriate if there was time to process the recording later on.

Recording a heartbeat in a setting like acute trauma would be beneficial if you can actually do the project and talk through that with the family later on when they process things, if there's a way that you could get the heartbeat and then just back off and wait. But if you had to do the entire project right then, there is potential that it could cause more harm than good. There's too much going on and too many decisions to make.

Sub-theme 2.2.2: Not Desired by Some Cultures. While Julie and Anne reported that they had not encountered cultural reasons for not offering this intervention, Brian stated that some people may not see a need for this intervention because of religious or cultural beliefs around death and the afterlife.

Sub-theme 2.2.3: When There is No Rapport. Two informants felt that if there is no rapport with the family, a heartbeat recording may not be appropriate to offer. Brian

pointed out that time with the family beforehand is especially important for patients who are at end-of-life.

To me that that has to do with, again, timing, and the time that we could and should have with these people. And when it shouldn't be offered is sometimes at the very end-of-life, when they have no idea who we are.

Anne felt similarly and stated that this was a situation where “it would be absolutely contraindicated.

Sub-theme 2.2.4: Not Ideal for Everyone. There may be situations where a heartbeat recording is not the right intervention. Julie and Brian both encouraged music therapists not to pressure patients or family into doing one. Brian noted that some patients and families might not desire legacy work, stating, “There are a lot of people who may not ever want to think about even the thought of listening to their loved one’s heartbeat after they’re gone.” Julie spoke similarly, and stated, “It’s not something that we need to force on them in any way.”

Theme 2.3: Navigating Copyright and Privacy Concerns

Often, copyrighted music is used in heartbeat recording projects because it is meaningful to the patient or family. Guidance on this is not clear, and informants reported navigating this in different ways, such as only using live recordings, not receiving compensation, and using heartbeat recordings only in private spaces. Patient confidentiality can also be an important consideration when creating heartbeat recording projects.

Sub-theme 2.3.1: Live Recordings. All three informants reported that they generally use live music rather than the recorded version, which they felt was sufficient to meet copyright laws. Two informants noted that it was rare they would use the original recording,

but Julie noted that it was sometimes indicated when “the recording itself was special to the family.” No informants reported concern regarding copyright law, and one stated, “I don’t ever worry about it.”

Sub-theme 2.3.2: No Financial Compensation. All three informants also expressed that they navigate copyright laws by not receiving financial compensation for their projects. Anne stated, “We don’t sell or receive any money from these. ... As far as copyright goes, it’s us playing it to give to them as a gift and there’s no monetary exchange.” Brian reported that he had reached out to performing colleagues for advice regarding copyright and had been informed that not charging for the product was an acceptable way to avoid issues with copyright law. It is worth considering that while music therapists might not receive payment directly for a heartbeat recording project, music therapists are paid for their services, which might include the clinical and/or production time necessary to create the recordings.

Sub-theme 2.3.3: Where the Project is Used. Performing copyrighted music typically requires a license. Brian stated that there would likely not be an issue with copyright law because the legacy project recordings are played in “mostly private places.” Regarding the other spaces where these recordings might be played, he added, “If it is being played in a public place like a funeral or church, mostly they have paid for that licensure to play anything that they ever want to.” This introduces the question of whether it is the responsibility of the music therapist to ensure that licensing has been acquired by these organizations.

Sub-theme 2.3.4: Confidentiality. Regarding patient confidentiality, two informants spoke about identifiability and protecting patient files. Anne and Julie both commented on the identifiability of heartbeats. Julie stated, “With our risk department involved, we

determined that a heartbeat recording is not identifiable information, so that's okay to keep.” Anne’s organization was not clear regarding whether heartbeats were identifiable information, so she reported that she is careful to obtain permission before sharing a heartbeat anywhere else. Julie and Anne also are careful to keep patient information unidentifiable to their organization’s standards. Julie stated, “For HIPAA compliance, we just have first name last initial on our saved documents.” Anne similarly abbreviates or encodes patient names. Both Anne and Julie reported protecting the files for the heartbeat recording projects as well. Julie stated, “We don't keep the actual files on our computer, they're just saved on a hard drive externally.”

Theme 2.4: Effect on the Music Therapist

Heartbeat recordings can be an emotional intervention for the music therapist as well as for the patient and family. When asked if there were times when this intervention might be emotionally difficult for the music therapist, Julie stated, “Yeah, absolutely.” Julie reported that she often seeks support from others to provide this intervention.

During those [difficult sessions], thankfully we are never alone at a hospital. There is usually somebody else working, so sometimes we will go together even so they can hold the iPad while I’m recording. Just to have another set of hands to help with recording devices and stuff is really helpful, and to have that moral support is really helpful.

Julie also spoke about self-care after experiencing sessions that were close to a time of death.

In our office, we also have a little ritual that we do when a child dies. We have a little singing bowl, and then we have rocks that we write the patient's name on and take time to say memories that we have with them or their family. And then we have a

moment of gratitude in silence. Then, we put the rocks in the singing bowl. That is something that has been beneficial to our team and is newer to us, for our processing as well.

Anne observed that heartbeat recording projects can have a profound effect on the music therapists caring for the patient and family. She shared a clinical example of when the death of a patient affected the whole team.

Sharing an office, we would each go see some of these same patients. We had crossover on who was covering different areas, so we would know some of the same stories of the patients. There were three of us who were really just brought to tears by this story. We took time together, all three of us, and recorded those songs using multiple instruments and harmonies. It was more complex than other projects. While we were doing it, I remember we all just started crying. It was really tough, but it was really kind of cool because it became an outlet for all of us to process that, just by being able to give them this project.

Anne also reported that these projects could offer music therapists an opportunity for closure of a patient's death.

The patients that I followed for a long time, if their journey did end in death and I was there at end-of-life, I craved wanting to do a heartbeat project for them because it was my way of wanting to do one more thing. It really was helpful to all of us.

Content Area 3: Organizational Involvement

Music therapists who use heartbeat recordings in their clinical work often work within organizations such as hospitals or hospices. These organizations can be part of funding the equipment necessary for heartbeat recordings. They are also often made up of

administrative and interdisciplinary teams that are part of providing quality care, including heartbeat recordings, to the patients alongside music therapists.

Theme 3.1: Funding

Informants shared that funding for equipment came from grants and organizational budgets. Anne received funding from a departmental budget but added that “eventually the palliative care unit purchased the equipment themselves.” Julie and Brian received funding from both grants and organizational budgets. Brian stated,

Every place that I've requested these, it's just like requesting an instrument. So, I've been lucky in my jobs I've had inside hospitals where the funding either was reimbursable or we worked on some sort of grant to get anything that we wanted.

Theme 3.2: Involving the Interdisciplinary Team

Interdisciplinary teams and administrations are part of providing quality care to patients and can provide important support to music therapists. Informants reported that it can be important to provide education about heartbeat recordings to the interdisciplinary team and administration to avoid misunderstandings that can result in unwanted pressure.

Sub-theme 3.2.1: Educate the Team. Anne recommended that music therapists considering introducing this intervention discuss it with administration prior to implementing it. She stated, “I think that this is something that is really good to have a whole team on board.” This may also be important given that sometimes music therapists are not the ones to introduce heartbeat recordings to the family. Julie shared that in her organization, “Usually spiritual care, social work, child life, or palliative is the one to present it, and they introduce it with other end-of-life interventions as well, like handprints, footprints, hand molds,

pictures or something.” Julie recommended providing education to the staff who are presenting it to patients, and she mentioned that her team has a printout they give to staff.

Anne stressed the importance of educating teams to not promise this intervention, especially at end-of-life.

One of the things that was constantly an education, that I was always having to say, was for the team to not promise this to anybody. We would come across that several times. “Oh, we have music therapists, and they can do this project for you.” And they page us and we’re across the hospital and we’re coming to cover that unit in the afternoon, but the patient dies. That was the biggest thing.

Brian and Anne both said that teams sometimes just want one more thing to offer to patients and might not consider appropriateness. Brian discourages staff from offering this intervention without considering what the benefit might be.

If it is just a one-time thing, we also need to be really careful with our coworkers offering this when they maybe shouldn’t just because they think that it’s one more thing that we can offer. If the family doesn’t understand why and how we’re doing this, or they don’t have a family that this is going to, we have to [ask] ourselves why are we doing it. There should always be this “Why?” in the background, and, “Who’s the recipient or participant in this?”

Anne sometimes has requested that medical staff not talk to patients about heartbeat recordings because of this.

Honestly, we asked them not to tell the patients about it the same way [we do] with music therapy. We found that their version of what it is is different than what it actually is. We would just ask for their consults to us and tell them what we’re

looking for. Again, the subjective kinds of things, like if there's a patient who's really musically inclined or if there's a patient who has young kids, or things like that. We told them what to be on the lookout for to then refer us to them.

Brian also noted that it may be helpful to remind clinical staff not to offer a heartbeat recording before discussing it with the music therapist.

You come to find out that it might be a handful of people who continue to offer this without talking to one of us first. Have a quick conversation about it and say, "The family doesn't know me. They don't know why we're doing this. They need some more time with it before we're just coming in with this equipment and then giving it to them, not for their own reason but for your reason."

Sub-theme 3.2.2: Support from the Team. Julie reported that connecting with other members of the interdisciplinary team can be meaningful for the patient and can provide additional emotional support to the music therapist.

If this is the third heartbeat recording that I've done this week and I just can't do it anymore, sharing that responsibility and doing that together [is helpful]. If the family connected with spiritual care person that's on that unit, [have] them join, or [have] the child life specialist that the family has connected with, or perhaps the child life specialist [can do] handprints at the same time or something. Having someone on your team to be there with you and you're there for them as well, I would say that's the best.

Brian observed that sometimes other members of the clinical team can handle the one-time referrals when music is not needed.

I don't think we own heartbeat recording, and I taught the child life specialist how to do them as soon as I got to this hospital four years ago. It was also a way for me to get out of those last-minute referrals because they were already doing those last-minute fingerprints and animals and things like that. This is just one more thing that they could do, and I didn't have to do any music part of it.

Sub-theme 3.2.3: Pressure from Medical Staff. Two informants experienced feeling pressured by medical staff to provide a heartbeat recording project when a patient might not be ready. Anne reported this happening most often when patients were close to death.

One of the biggest obstacles I came across a lot was the very first time I would introduce this project to people, the doctors who had heard about this would be like, "Hey this person's dying right now, you need to go in there and do this!" Julie found that staff might do this when they were concerned that families would regret not getting a heartbeat recording.

There's a lot of concern with our staff that the family will change their mind after it's too late. They'll wish they had it after the child has already died and at that point, we obviously can't do it. There is a fine line between respecting their wishes and trying to eliminate any regrets in the future. There are just some things we can't control.

Chapter 6: Discussion

This chapter integrates the findings from the survey and interviews about the use of heartbeat recordings in music therapy practice. These findings are applied to the original research questions and discussed so that music therapists can gain a working knowledge of the intervention. This chapter concludes with implications of the findings for music therapists and recommendations for future research.

Restatement of Purpose

The purpose of this study was to describe the current practice and clinical use of heartbeat recording projects as a music therapy intervention. The research questions included below were developed to gather insight from board-certified music therapists regarding their use of heartbeat recordings in music therapy. Each research question is presented along with relevant findings from the online survey and interviews.

Question 1: What are the Barriers for Music Therapists Interested in Using this Intervention?

Barriers

This study uncovered music therapists' perceptions of barriers to the use of heartbeat recordings in music therapy. Even though heartbeat recordings were reported to be in use with a variety of populations and clinical goals, the most commonly reported barrier was not working in a relevant setting or with a relevant population. This is likely because the possible uses of heartbeat recordings have not been explored in the literature. Access to funding and

equipment was also found to be a barrier. While grants and budgets were identified as sources for funding, these sources may be difficult to access for music therapists working in non-hospital settings. Music therapists also reported not knowing where to find training and not feeling comfortable with the technology. Music therapists most commonly reported learning to create a heartbeat recording from a colleague or supervisor, which may suggest that this intervention is spreading in a grassroots way or that there is a lack of available instructional resources, resulting in direct instruction as the only means of learning. This possibility is reinforced by the interview responses that indicated an initial difficulty in learning how to create heartbeat recordings. It was also reported that some work settings do not support the use of heartbeat recordings, which suggests that there may be organizational barriers to heartbeat recordings. While these may be related to privacy or licensing issues as was indicated by one survey respondent who wrote in, “My IT department will not approve the recording apps necessary on my device, stating it is not HIPPA [*sic.*] compliant,” the reasons for this barrier were not explored further in this study. There was also concern reported about the benefit, privacy issues, and cultural appropriateness of heartbeat recordings. Some music therapists simply were not familiar with the intervention.

Resources

Various resources for addressing these barriers were identified. Direct instruction from a music therapist colleague or supervisor was reported to be the most helpful approach to learning to create heartbeat recordings. Workshops, trainings, and CMTEs were also identified as helpful methods of instruction, and these may be more available as this intervention grows in popularity. Nurses were reported to be a resource regarding the specifics of finding the heartbeat and adjusting the environment to contribute to a better-

quality sound, and this study's informants expressed that nurses are largely willing and eager to help. This finding may highlight a need for clinical training on how to use a stethoscope and on the appropriate bedside manner for hands-on care. Some survey results indicated that training in production or assistance from people with an understanding of technology, such as Apple store employees, can help music therapists learn how to create heartbeat recording projects. These resources may be especially helpful for the mixing portion of the project. It was also reported that trial and error can be an effective method of learning.

Question #2: Who is Using Heartbeat Recordings as a Music Therapy Interventions?

Prior to this study, no information was available about which music therapists were using heartbeat recordings in music therapy. Over half of the survey respondents did not have experience with heartbeat recordings yet still responded to the survey, which suggests that there may be significant interest in the intervention. Demographic information gathered from survey respondents who indicated that they had experience with heartbeat recordings provided useful knowledge about who is currently using heartbeat recordings as a music therapy intervention. At the time of the survey, the majority of music therapists using heartbeat recordings were White, female, between the ages of 20-29, and had been practicing for 1 to 5 years, which is representative of the majority of board-certified music therapists across the United States according to the AMTA Workforce Analysis (AMTA, 2020f). Respondents primarily did not identify as having a disability and most practiced from a Humanistic orientation. The majority held a master's degree in music therapy, whereas the Workforce Analysis found that there were slightly more music therapists who practice with an undergraduate degree in music therapy. The distribution of respondents by region was similar to the AMTA Workforce Analysis and all regions were represented, with the majority

of respondents using heartbeat recordings practicing in the Great Lakes Region, followed by the Southeastern Region. An exception to this similar distribution is the Mid-Atlantic Region, which had a lower representation than might be expected based on the Workforce Analysis and given its proximity to the Great Lakes Region and Southeastern Region. It was most common for music therapists using this intervention to have 2 to 5 years of experience with it, which is consistent with the fact that the first academic research about heartbeat recordings in music therapy was published in 2018.

Question #3: With Whom are Heartbeat Recordings Being Used?

Available literature has explored the use of heartbeat recordings in perinatal hospice (Schreck & Economos, 2018) and with bereaved parents (Andrews et al., 2020; Walden et al., 2020). This study found that this intervention is being used in a variety of settings and populations, including children's medical hospitals, hospice and palliative organizations, adult medical hospitals, hospice in-patient centers, skilled nursing facilities or senior care homes, PICU/NICU/CICU, private practices, pediatric/perinatal hospices, outpatient/inpatient oncology, pediatric skilled nursing facilities, palliative care units, and mental health hospitals. The majority of music therapists in this study reported that they use heartbeat recording in children's medical hospitals, despite the fact that more music therapists currently work in hospice and bereavement organizations than children's hospitals (AMTA, 2020c). Heartbeat recordings are used with populations including people with serious or terminal illness, people who are actively dying, people without serious illness, transplant patients, people with eating disorders, and pregnant mothers. A number of survey respondents also wrote in that they might use this intervention with anyone, which was reinforced by interview responses.

Question #4: How are Heartbeat Recordings Used in Music Therapy?

A wide variety of possible goals for heartbeat recordings were reported in this study, as well as information about the clinical process of using the intervention. Information was gathered regarding what to do when a patient requests a heartbeat recording but is not interested in music therapy, how to educate the interdisciplinary team about heartbeat recordings, how to introduce the project, how to create the project, and how to edit and deliver the project.

Goals

The available literature on heartbeat recordings speaks to the effectiveness of the intervention for meaning-making, expression of grief, and coping in legacy work (Schreck & Economos, 2020; Walden et al., 2020). This study found that legacy work is a primary goal for the intervention, and also found other relevant goals. Music therapists reported using heartbeat recordings to help individuals connect with their inner pulse, communicate feelings of love, commemorate a particular amount of time in the hospital, adjust to a newly-transplanted organ, express gratitude toward an organ donor, and find reasons to live. One survey respondent wrote that “Initially, I thought heartbeat recordings were only for legacy projects and the dying; but it works wonders within the therapeutic healing relationship for an individual with themselves.” These diverse and meaningful goals are not currently represented in the literature.

Heartbeat Recording Alone

It was reported that patients sometimes will not be interested in music therapy but will desire a heartbeat recording. Data from the interview reflected that this type of project can still be beneficial for legacy work and may also open the door to music therapy services

for these patients. One interviewee said he might not bring up music if a heartbeat recording was all that was desired. Another noted that quickly getting the heartbeat and leaving can be a good way to meet the needs of families who are grieving and want privacy as well as a heartbeat recording. While music therapists might use interventions that are not music-based in the course of music therapy, it may be unusual for music therapists to be routinely asked to provide a quick product that is not music-based. This aspect of heartbeat recordings may benefit from future research.

Prior to Using the Project

Results from this study demonstrate that in some settings, the process of using heartbeat recordings in music therapy might begin with educating interdisciplinary teams and administration about what heartbeat recording projects are, who might be an appropriate patient, how, whether, and when to present the idea to patients, and the importance of not promising it to a patient at end-of-life. Education might also involve teaching other staff, such as Child Life Specialists, how to take heartbeat recordings, so that when a recording is desired simply as a product outside of the therapeutic process of music therapy, it can be offered.

Introducing the Project

This study found that prior to introducing the intervention, it may be important for the music therapist to be aware that heartbeat recordings can be perceived as being sad and that some patients are not interested in legacy work. The music therapist should get consent to proceed with the project and should educate the patient and family on what to expect when the music therapist is recording the heartbeat. This may be especially important if the heartbeat is difficult to find, which is often the case in situations where the heartbeat is weak,

there are respiratory issues, or there is noisy medical equipment nearby. If the music therapist is only able to find one good heartbeat, that can still be enough of an audio sample to loop for the project. Finally, the music therapist might offer to have a family member or a staff member with whom the patient has a good relationship use the stethoscope rather than the music therapist, for the patient's comfort.

Creating the Project

Schreck & Economos (2018) advocated for a process-oriented approach to heartbeat recordings when they wrote, "Although families appreciate having a physical product to cherish, the strength in this intervention lies in its flexibility to be offered as a process within the context of a music therapy" (p. 24). This study found that not all music therapists use this process-oriented approach. Some music therapists even reported encountering patients who wanted heartbeat recordings but were not interested in music therapy. Survey data indicated that while the majority of music therapists offer a heartbeat recording primarily once rapport has been established, for others it might depend on the clinical situation or it might be offered on the initial visit. This study also found that the majority of music therapists using this intervention do not communicate further about the project with the patient or family once it has been delivered, although some music therapists invite the patient or caregiver to initiate contact once the project has been delivered. Some music therapists feel that the project can be beneficial to families even without the opportunity to have a therapeutic process with the music therapist, but they noted the importance of the therapeutic process nonetheless.

This study found that even if there is only a one-time visit to create the heartbeat recording, it is important and possible for the music therapist to build rapport quickly. The music therapist might also discuss how the family plans to use the project and might involve

the patient or family in the process. These things might make the project more memorable, leading to greater use of it following the patient's death. This study revealed ways music therapists might involve the family, such as collecting messages or thoughts from the patient or family, inviting the patient or family to listen to the heartbeat, writing a song together to mix with the heartbeat, recording verbal messages to mix with the heartbeat, or improvising music to record over the heartbeat. The informants encouraged other music therapists to be creative about what they include in the project. Survey results indicated that the most common variety of heartbeat recording project is the heartbeat alone or the heartbeat with recreated music performed by the music therapist.

Editing and Delivering the Project

This study found valuable information regarding the editing and delivering of the heartbeat recording project. Results demonstrated that music therapists should discuss with the family how the family plans to use the project in order to guide the editing process. For example, if the recording will primarily be played in a car, it could have more bass, while if it will mostly be played on phone speakers, it could have more treble. It is considered valuable to try to keep the recording as authentic as possible and to only edit the sound to make it sound more like a heartbeat. While one informant reported that she edits projects outside of sessions, another encouraged music therapists to work together with the patient and family as much as possible, including during the editing process, to make the project more memorable. This is striking, given that only 3.2% of survey respondents reported mixing the audio during the session. This study also revealed a variety of formats for delivery of the completed project, including CDs, .mp3 files, thumb drives, QR codes, Soundcloud links, and recordable teddy bears. However, it was noted that recordable products like teddy bears

might become annoying over time, and music therapists were encouraged to discuss with the family how they plan to use the product.

Question #5: What Technology is Used to Create and Deliver Heartbeat Recordings?

Stethoscopes

A variety of stethoscopes are being used for heartbeat recordings. The most popular choice of stethoscope was a lapel microphone with stethoscope, followed by the Thinklabs digital stethoscope and then the Eko digital stethoscope. Other stethoscopes named include the Littman digital stethoscope, Steth IO, Paramed, Womb Music, Doppler, and ultrasound. While it was not the most commonly used, the Eko digital stethoscope was reported to be the favorite by music therapists who had used more than one, followed by the Thinklabs digital stethoscope. It was noted that some stethoscopes are better for certain populations; for example, one respondent selected the Thinklabs as a favorite, but reported that Womb Music was better for fetal heartbeats. Another reported that the Eko was better for stronger heartbeats, while the lapel mic with stethoscope was better for weaker heartbeats or in situations where there are respiratory issues. Digital stethoscopes with the ability to amplify the heartbeat were reported to be helpful.

Devices

Mac computers or laptops were most commonly reported to be used for project creation, followed by iPads or other tablets, but some music therapists reported using a Windows computer or laptop or an iPhone or other smartphone. One survey respondent wrote in that they recorded on a tablet and edited on a laptop, and because this survey question only allowed one response, it is possible that other music therapists similarly use multiple devices for different phases of the project.

Digital Audio Workstations

GarageBand was the most popular DAW reported for mixing heartbeat recordings. Other programs music therapists reported using include LogicPro, Audacity, Pro Tools, Ableton Live, Reaper, CuBase, Digital Performer, and Luna. A few music therapists reported using multiple programs. While GarageBand is not supported for Windows operating systems and reflects that the majority of respondents use Mac laptops and computers, several of the reported DAWs are available for Windows.

Question #6: What are Ethical Considerations for the Implementation of Heartbeat Recordings and the Associated Use of Technology?

As music therapists abide by a professional Code of Ethics, it is important to consider any ethical questions surrounding the music therapy practice. This study uncovered some ethical considerations around the use of heartbeat recordings in clinical practice. These include that heartbeat recordings can represent a trauma or traumatic time, that they may not be culturally appropriate, and that they may require building rapport prior to the intervention. Additionally, music therapists should be aware of privacy and copyright laws when creating heartbeat recordings.

Representation of a Trauma

This study found that heartbeat recordings in legacy work could represent a difficult time for families rather than simply a connection to their loved one, especially when the heartbeat is poorly functioning or obscured by lung sounds. Similarly, it may not be appropriate to offer a heartbeat recording when a person is dying from a sudden or acute trauma, or when there is not an opportunity to create and process the project with the family

later on. These traumatic situations are often very difficult for families and adding another decision in the moment in the form of a legacy project may feel overwhelming.

Cultural Appropriateness

Regarding heartbeat recordings, one survey respondent wrote, “I come from a different culture, where doing this is considered inappropriate and creepy,” which suggests that there is at minimum one culture in which heartbeat recordings would not be appropriate. This study found that there are mixed opinions on whether a heartbeat recording could ever be culturally inappropriate. While two informants reported they could not think of a cultural reason heartbeat recording would not be appropriate, the third thought that some people with particular cultural or religious beliefs about death and the afterlife may not see a need for this intervention. The questions around cultural appropriateness of this intervention remain unanswered and should be explored more fully in future research.

Rapport

The importance of building rapport prior to offering heartbeat recordings was unclear in the survey results. When asked at what point they offer to create a heartbeat recording, the majority of survey respondents indicated that they felt it should be once rapport was established, but the next most popular response was that it depended on the situation. Similarly, some interview responses indicated that rapport was very important while others indicated that it might not be. For example, one respondent stated,

At the start of the situation, if there is no therapist relationship, no really good explanation for the project, no discussion about how they could potentially use this in the future ... that's where it would be absolutely contraindicated.

Other interview responses indicated that there were times when the family wanted a heartbeat recording and nothing else, and that this seemed appropriate to provide. It is possible that music therapists are offering this intervention to patients and families without building rapport first, but that building rapport may be the best practice, since survey respondents were asked what they usually did rather than what they felt was best for the client. Further research on the role of building rapport prior to offering heartbeat recordings is recommended.

Privacy and Copyright

This study found that some music therapists have concerns about patient privacy and copyright laws with regard to heartbeat recordings. Some music therapists reported that they protect patient privacy by only using initials or first name and last initial on any product given to patients. Similarly, projects are often stored in locked files or external hard drives. Heartbeats have been determined to not be identifiable information.

Music therapists are navigating the murky waters of copyright in various ways. Interview data reflected that music therapists feel that primarily using live recordings of music, not receiving financial compensation, and using the product in private places or places where licensing would have been purchased (such as funeral homes or churches) protects them from issues with copyright. The question of playing copyrighted music in funeral homes or churches raises the question of whether the music therapist has an obligation to inquire about the institution's current licensing before a service where the recording is used. One music therapist admitted to not worrying about copyright and considered it unlikely that any artist would be upset with a music therapist using copyrighted music for music therapy purposes. No informants reported seeking licensing for copyrighted materials.

Limitations

Responses to one survey question indicated that respondents may have conflated “heartbeat recording” with “heartbeat recording project.” It is possible that uncertainty around these terms skewed data from questions about learning how to take a “heartbeat recording,” particularly with a digital stethoscope. Additionally, the majority of respondents with experience using heartbeat recordings worked in children’s hospitals. Therefore, the findings of this study may be less applicable to music therapists who use this intervention with adults.

Implications for Music Therapists

Based on the findings from this study, heartbeat recordings and heartbeat recording projects are useful for a variety of populations, settings, and goals. It is possible that the association of heartbeat recordings with legacy work limits music therapists’ perception of the intervention’s relevance for other goals. While heartbeat recordings seem to be most often used for legacy work, this study found that they can also help individuals connect with their inner pulse, communicate feelings of love, commemorate a particular length of stay in a hospital, adjust to a newly-transplanted organ, express gratitude toward an organ donor, or explore reasons to live. Music therapists are encouraged to explore these and other possibilities in clinical work.

This study also found that it can be difficult to learn new kinds and uses of technology, especially when resources are few. Music therapists are encouraged to seek advice from more experienced music therapists, to make use of available workshops, trainings, and CMTEs, and to keep practicing with the knowledge that these skills can be developed. It is hoped that this study will provide some of the information needed for music

therapists to begin exploring heartbeat recordings, and that more resources for music therapists interested in using heartbeat recordings will become available soon.

This study found that there are a number of reasons a client may not desire a heartbeat recording, including cultural inappropriateness or being an unwanted reminder of a traumatic time, and music therapists are encouraged to remain sensitive to this tension. Similarly, it is important for music therapists to build rapport with patients and families prior to offering this intervention, even if it is necessary to do so in a short amount of time. Legacy work is often completed during a tender time, when patients and family are grieving an anticipated loss of life, and it should be treated carefully. When heartbeat recordings are used for legacy work, music therapists are encouraged to be creative, discuss the use of the project, and involve the patient and family in the project as much as possible.

Finally, music therapists are urged to practice to the standards set by the AMTA's Code of Ethics when using interventions that involve protected information and copyrighted material. Unfortunately, the law is unclear regarding music therapists' use of copyrighted materials. This study found that music therapists and organizations may have concerns about using heartbeat recordings in music therapy for this reason, and that music therapists may have differing levels of awareness of copyright law at this time. While there is a legal grey area around music therapists' use of copyrighted material for music therapy purposes, and it may be unlikely that music publishers or artists would be upset with the use of their copyrighted music for a legacy project, music therapists should be aware of the legal issues and professional risks present when using copyrighted material. It is hoped that a legal exemption will be made for music therapists under copyright law. Music therapists are also

expected to protect patient privacy and confidentiality of information when creating legacy projects or engaging in self-care practices.

Recommendations for Future Research

This study has uncovered several areas of research on the topic of heartbeat recordings in music therapy which would benefit from further research. First, there is a dearth of research on the use of heartbeat recordings in clinical music therapy. This study has established an overview of current practice and has uncovered a variety of ways heartbeat recordings are being used which have not been represented by the literature and would benefit from additional research. Research determining the importance of building rapport or comparing the process-oriented and product-oriented versions of the intervention would be beneficial to music therapists using this intervention for legacy work. Similarly, research exploring heartbeat recordings as a non-musical product created apart from the process of music therapy is recommended, especially as the product becomes more in-demand with various client bases. Finally, the question of cultural appropriateness of this intervention also remains unanswered and should be explored more fully in future research to ensure culturally sensitive practice.

Conclusion

Heartbeat recordings are used in music therapy practice across the United States and are quickly growing in popularity as a memorable and useful intervention. While there are a variety of clinical uses, music therapists largely use heartbeat recordings in combination with other media for legacy work. It can be difficult to learn how to use the necessary technologies, but both the process and product of heartbeat recordings can be significant for

patient, family, and music therapist. Heartbeats exist as a symbol of identity and life and should be used conscientiously in the meaningful work of music therapy.

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Appendix A: Online Survey Questions

Section 1: Barriers to Practice

1. Have you ever utilized heartbeat recording projects in your music therapy practice?

Choose:

Yes

No

If yes: Skip to Question 3.

If no: See Question 2.

2. What, if any, barriers have kept you from utilizing heartbeat recording projects in your music therapy practice?

Choose all that apply:

I don't have access to funding for equipment

I don't feel comfortable with the technology

I don't know where to find training

I don't work in a relevant setting

I don't work with a relevant population

This intervention is not supported by my work setting

There are no barriers

Other (please specify)

Survey ends here for those who respond 'No' to Question 1.

Section 2: Current Practice of Heartbeat Recording Projects

3. In what setting have you used heartbeat recording projects?

Choose all that apply:

Children's medical hospital

Adult medical hospital

Hospice and palliative organization

Hospice in-patient center

Skilled nursing facility or senior care home

Other (please specify)

4. How much experience do you have using heartbeat recording projects?

Choose:

0-1 year

1-2 years

2-5 years

5+ years

5. How did you learn to take recordings of a person's heartbeat?

Choose all that apply:

I learned from informal resources, i.e., Youtube, Google
I learned from scholarly work(s), i.e., journal articles, books
I learned from a music therapist colleague/supervisor
I learned from a workshop, training, or CMTE
I learned from a medical professional (i.e., nurse, doctor)
Other (please specify)

6. How did you learn to create heartbeat recording projects with music?

Choose all that apply:

I learned from informal resources, i.e., Youtube, Google
I learned from scholarly work(s), i.e., journal articles, book
I learned from a music therapist colleague/supervisor
I learned from a workshop, training, or CMTE
Other (please specify)

7. If you learned aspects of heartbeat recording projects from more than one of the following sources, which method of learning was most helpful?

Choose:

Informal resources, i.e., Youtube, Google
Scholarly work(s)
Music therapist colleague/supervisor
Workshop, training, or CMTE
Not applicable/I only learned from a single source

8. How often do you create heartbeat recording projects?

Choose:

Very frequently (once per week or more)
Somewhat frequently (several times per month)
Somewhat infrequently (occasionally throughout the year)
Very infrequently (less than a few times per year)

9. With whom do you use heartbeat recording projects?

Choose all that apply:

Individuals without serious illness
Individuals with serious illness
Individuals with terminal illness
Individuals who are actively dying
Other (please specify)

10. At what point do you usually offer to create a heartbeat recording project?

Choose:

During the initial visit

Once rapport has been established (after a few visits)

Only after significant clinical work has been done

Other (please specify)

11. What do you usually include in a heartbeat recording project?

Choose all that apply:

Heartbeat alone

Heartbeat and pre-recorded music

Heartbeat and recreated music performed by music therapist

Heartbeat and original song performed by music therapist

Heartbeat and recreated song performed by patient/family

Heartbeat and original song performed by patient/family

Other (please specify)

12. What portion of the heartbeat recording project usually occurs during the music therapy session?

Choose all that apply:

Heartbeat recording

Music selection

Music recording

Audio mixing

Delivery of completed project

13. What information do you gather from the patient or family related to and prior to the project?

Choose all that apply:

Patient's messages for family

Family's thoughts about patient

Important people in the patient's life

Meaningful song choices

Stylistic music preferences

Other (please specify)

None

14. Which of the following do you adjust in the editing process?

Choose all that apply:

Volume of the heartbeat

Sound of the heartbeat

Tempo of the heartbeat

Length of prerecorded music

Tempo of prerecorded music

Other (please specify)

None

15. What communication usually happens once the project has been delivered?

Choose:

I do not communicate further about the project with the patient/caregiver once it has been delivered

I follow up with the patient/caregiver once to discuss/process the project

I follow up with the patient/caregiver multiple times to discuss/process the project

Other (please specify)

16. How is the heartbeat recording project usually delivered to the recipient(s)?

Choose:

Emailed audio file (.mp3, .wav, etc.)

Mailed CD or thumb drive

Hand-delivered CD or thumb drive

Other (please specify)

17. What stethoscope do you usually use to record a person's heartbeat?

Choose:

Eko digital stethoscope

Thinklabs digital stethoscope

Lapel mic with stethoscope

Other (please specify)

18. If you have used multiple stethoscopes to record heartbeats, which did you like best?

Choose:

Eko digital stethoscope

Thinklabs digital stethoscope

Lapel mic with stethoscope

Other (please specify)

I have only used one stethoscope

19. What digital audio workstation do you use to create heartbeat recording projects?

Choose:

Garageband

Audacity

LogicPro

Other (please specify)

20. What device do you use to create heartbeat recording project?

Choose all that apply:

Mac computer/laptop

Windows computer/laptop

Iphone or other smartphone

Ipad or other tablet

Other (please specify)

Section 3:
Demographic Information

21. How do you currently describe your gender identity?

Choose:

Female

Male

Non-binary

Prefer not to answer

Prefer to self-describe: _____

22. What is your ethnicity?

Choose all that apply:

Asian

Black or African American

Hispanic, Latinx, or Spanish Origin

Middle Eastern or North African

Native American or Alaska Native

Native Hawaiian or Other Pacific Islander

White

Other (describe)

Prefer not to answer

23. Do you identify as having a disability?

Choose:

Yes

No

Prefer not to answer

24. What is your age?

Choose:

20-29

30-39

40-49

50+

25. How many years have you been a credentialed music therapist?

Round to the nearest whole number:

26. What is your highest level of education obtained?

Choose:

Undergraduate degree in music therapy

Equivalency in music therapy

Master's degree in music therapy

Master's degree in a related field

Doctoral degree in music therapy

Doctoral degree in a related field

27. In what region of AMTA did you practice when using heartbeat recording projects?

Choose:

Great Lakes Region

Mid-Atlantic Region

Midwestern Region

New England Region

Southeastern Region

Southwestern Region

Western Region

28. How do you describe your theoretical orientation?

Choose:

Analytical Music Therapy

Cognitive-Behavioral

Existential

Gestalt

Humanistic

Psychodynamic

Resource-Oriented Music Therapy

Eclectic (please specify)

Other (please specify)

Section 4:

Interview

29. If you have more than one year of experience using heartbeat recordings and more than one year of clinical music therapy experience, would you be willing to participate in a follow-up interview regarding the use of heartbeat recordings in music therapy?

Choose:

Yes

No

30. If you answered yes to question #, please enter your name and email address below.

Thank you for your time and participation in this survey. Your response has been recorded.

Appendix B: Follow-up Interview Guide

1. How was your equipment for heartbeat recordings funded?
2. Who would be an ideal candidate for this intervention and why?
3. Are there any settings or situations where a heartbeat recording might be contraindicated?
4. How much time is ideal to create and process a heartbeat recording with a patient and/or family? If time is limited, how do you balance the importance of the process and the product?
5. Have you experienced patients wanting a heartbeat recording but not music therapy? How do you navigate this request?
6. How do you navigate privacy concerns and copyright with regards to heartbeat recording projects?
7. Would you like to share any unique ideas of items to include in a heartbeat recording project, or methods of delivery of the completed project?
8. Do you have any advice for music therapists who are interested in using this intervention?
9. Please share a de-identified story describing your use of a heartbeat recording project in your clinical work.

Appendix C: Informed Consent for Participation in the Online Survey

HEARTBEAT RECORDINGS IN MUSIC THERAPY: A SEQUENTIAL-EXPLANATORY MIXED METHODS STUDY

Emily P. Kiefer, Principal Investigator, pateer@appstate.edu, 919-271-1151
Christine P. Leist, Faculty Advisor, leistcp@appstate.edu, 828-262-6663

Dear Board-Certified Music Therapist,

You are invited to participate in a survey concerning the use of heartbeat recording projects in music therapy. This survey is part of a research study being conducted at Appalachian State University to fulfill thesis requirements for the Master of Music Therapy Degree.

Your contact information is being used with permission from the Certification Board for Music Therapists. Your survey responses will remain anonymous and will not be attached to your email. The survey itself is hosted on Qualtrics, which is a secure site that does not store or track your email. As a part of the survey, you will be invited to provide contact information for a subsequent interview. Participation in this subsequent interview is completely voluntary. All data will be included in the researcher's master's thesis and may be submitted for publication and presentation at AMTA conferences.

The survey should take no more than 20 minutes and includes questions regarding interest in and barriers to using heartbeat recordings, the clinical use of heartbeat recordings, and demographic information. Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time without consequences. There are no foreseeable risks to participating in this survey. No compensation is provided for completing the survey.

If you have questions about this research study, you may contact myself or Dr. Christine Leist at the contacts listed above. You may also contact the Appalachian State University Institutional Review Board at 828-262-4060.

The Appalachian State University Institutional Review Board has determined that this study is exempt from review. By completing the online survey, you acknowledge that you at least 18 years old, have read the above information, and agree to participate.

Thank you for your participation,

Emily P. Kiefer, MT-BC, Principal Researcher
Candidate for Master of Music Therapy
Appalachian State University, Hayes School of Music

Appendix D: Informed Consent for Participation in Follow-up Interview

HEARTBEAT RECORDINGS IN MUSIC THERAPY: A SEQUENTIAL-EXPLANATORY MIXED METHODS STUDY

Emily P. Kiefer, Principal Investigator, pateer@appstate.edu, 919-271-1151
Christine P. Leist, Faculty Advisor, leistcp@appstate.edu, 828-262-6663

Dear Board-Certified Music Therapist,

As part of my thesis requirements for the Master of Music Therapy degree at Appalachian State University, I am conducting interviews about the use of heartbeat recordings in music therapy. You are invited to participate in this portion of the research due to having at least one year of experience with heartbeat recordings and your response to the survey question indicating your interest in participating.

The interview will be conducted via Zoom and will last approximately one hour. The interview will be video recorded for the purposes of transcribing your answers following the interview. Since voice recordings and facial images are identifiable, there is always a risk that someone who does not have permission may see the recording and find out what you said during the study. In order to protect your privacy and keep your responses confidential, the video file will be stored on a password protected laptop. This file will be transcribed and sent to you via email to review for accuracy. The file will be deleted following transcription and member checking. The information from the interviews, including significant quotes, will be used in my thesis and may be considered for publication or presentation at AMTA conferences. Any material used will be anonymous.

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time without consequence. You have the right to refrain from answering any question during the interview. If you have questions about this research study, you may contact myself or Dr. Christine Leist at the contacts listed above.

The Appalachian State University Institutional Review Board (IRB) has determined that this study is exempt from IRB oversight.

I acknowledge that I have read the above information and have had the opportunity to ask questions about the research and receive satisfactory answers. I have at least one year of experience using heartbeat recordings in music therapy. I agree to participate in the study.

Participant Signature

Date

Sincerely,
Emily P. Kiefer, MT-BC

Appendix E: Letter for IRB Approval/Exemption

From: Nat Krancus, IRB Administrator

Date: 1/25/2021

RE: Notice of Exempt Research Determination

STUDY #: 21-0173

STUDY TITLE: Heartbeat Recordings in Music Therapy: A Sequential-Explanatory Mixed-Methods Study

Exemption Category: 2.Survey, interview, public observation

NOTE: This project, like all exempt and non-exempt research with human subjects at Appalachian State University, is subject to other requirements, laws, regulations, policies, and guidelines of the University and the state of North Carolina. As of August 24, 2020 and until further notice, this includes the requirement by the Office of Research to pause in-person research projects until it receives an additional review to ensure the existence of an adequate COVID-19 mitigation protocol. Please see the full requirement on the Research Protections website, as well as answers to questions you may have

This study involves no more than minimal risks and meets the exemption category or categories cited above. In accordance with the 2018 federal regulations regarding research with human subjects [45 CFR 46] and University policy and procedures, the research activities described in the study materials are exempt from IRB review. If this study was previously reviewed as non-exempt research under the pre-2018 federal regulations regarding research with human subjects, the Office of Research Protections staff reviewed the annual renewal and the initial application and determined that this research is now exempt from 45 CFR 46 and thus IRB review.

What a determination of exempt research means for your project:

1. The Office of Research Protections staff have determined that your project is research, but it is research that is exempt from the federal regulations regarding research.
2. Because this research is exempt from federal regulations, the recruitment and consent processes are also exempt from IRB review. This means that the procedures you described and the materials you provided were not reviewed Office of Research Protections staff, further review if these materials are not necessary, and you can change these procedures and materials without review from this office. You can use the consent materials you may have provided in the application, but you can change the consent procedures and materials without submitting a modification. **Note that if your consent form states that the study was “approved by the IRB” this should be removed. You can replace it with a sentence that says that the study was determined to be exempt from review by the IRB Administration. In addition, be sure that the number you have listed for the IRB is 828-262-4060.**

3. **You still need to get consent from adult subjects and, if your study involves children, you need to get assent and parental permission.** At the very least, your consent, assent, and parental permission processes should explain to research subjects: (a) the purpose, procedures, risks, and benefits of the research; (b) if compensation available; (c) that the research is voluntary and there is no penalty or loss of benefits for not participating or discontinuing participation; and (d) how to contact the Principal Investigator (and faculty advisor if the PI is a student). You can also use exempt research consent template, which accounts for all of these suggested elements of consent: <https://researchprotections.appstate.edu/human-subjects-irb/irb-forms>.
4. **Special Procedures and populations for which specific consent language is suggested.** Research involving children, the use of the SONA database for recruitment, research with students at Appalachian State University, or MTurk should use the specific language outlined by Office of Research Protections on our website: <https://researchprotections.appstate.edu/human-subjects-irb/consent-corner>.
5. **Non-procedural Study Changes:** most changes to your research will not require review by the Office of Research Protections. However, the following changes require further review by our office:
 - the addition of an external funding source,
 - the addition of a potential for a conflict of interest,
 - a change in location of the research (i.e., country, school system, off site location),
 - the contact information for the Principal Investigator,
 - the addition of non-Appalachian State University faculty, staff, or students to the research team, or
6. **Changes to study procedures.** If you change your study procedures, you may need to submit a modification for further review. Changes to procedures that may require a modification are outlined in our SOP on exempt research, a link to which you can find below. Before submitting a modification to change procedures, we suggest contacting our office at irb@appstate.edu or (828)262-4060.

Investigator Responsibilities: All individuals engaged in research with human participants are responsible for compliance with University policies and procedures, and IRB determinations. The Principal Investigator (PI), or Faculty Advisor if the PI is a student, is ultimately responsible for ensuring the protection of research participants; conducting sound ethical research that complies with federal regulations, University policy and procedures; and maintaining study records. The PI should review the IRB's list of PI responsibilities.

To Close the Study: When research procedures with human participants are completed, please send the Request for Closure of IRB Review form to irb@appstate.edu.

If you have any questions, please contact the IRB Administrator at (828) 262-4060.

Best wishes with your research.

Important Links for Exempt Research:

Note: If the link does not work, please copy and paste into your browser, or visit <https://researchprotections.appstate.edu/human-subjects>.

1. Standard Operating Procedure for exempt research (#9):

https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/sop_9_approved_1.21.2019.pdf

2. PI responsibilities:

<https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/PI%20Responsibilities.pdf>

3. IRB forms: <http://researchprotections.appstate.edu/human-subjects/irb-forms>

Vita

Emily P. Kiefer, MT-BC grew up riding horses, reading, and playing flute in Apex, NC. Her love of flute led her to study with Dr. Brooks de Wetter-Smith at the University of North Carolina at Chapel Hill, and she graduated in 2015 with a Bachelor of Arts in Music and Philosophy. After discovering music therapy, Emily attended Appalachian State University, where she earned an Equivalency in Music Therapy in 2018. She completed a clinical music therapy internship with Trellis Supportive Care (formerly Hospice and Palliative CareCenter) in Winston-Salem, NC and subsequently received her board certification. In 2019, she returned to Trellis Supportive Care as a Music Therapist and Complementary Therapies Coordinator and also entered the Master of Music Therapy program at Appalachian State University. Her coursework focused on music therapy with hospice patients and expressive arts therapy, and she completed two levels of training in the Bonny Method of Guided Imagery and Music. Following graduation, she plans to continue her work at Trellis Supportive Care and her training in the Bonny Method. Emily is a member of the American Music Therapy Association, the Music Therapy Association of North Carolina, and the Association for Music and Imagery.