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**A Narrative Approach to Songwriting in a Pediatric Medical Setting:
Understanding Caregivers' Lived Experience through Development of a Method**

Capstone Thesis

Lesley University

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Mental Health Counseling: Music Therapy

Dr. Rebecca Zarate

Abstract

This exploratory Capstone project focused on understanding caregivers' lived experience through a narrative-informed songwriting approach. Previous literature has explored the use of narrative therapy and songwriting with caregivers, but little research has focused on a narrative-informed approach to songwriting with caregivers of children in a pediatric hospital. This four-phase songwriting intervention was carried out over the course of four sessions with two caregivers (a mother and father) of one of the patients on the medical units at a Children's Hospital in the metro Boston area. Data collection and analysis followed a qualitative iterative arts-based procedure that included writing down the narrative of each session as well as the researcher's own self-reflection through violin improvisation. Four main themes were lifted from the self-reflections, including: Everything at once/Overwhelm; A moment of calm; Music as containing/supportive; and Connection through music. The results indicate that providing a space for caregivers to process their narratives through music can support the caregivers' own reflection and understanding of life events, and simultaneously strengthen the therapeutic relationship.

Keywords: music therapy; narrative therapy; caregivers; pediatric hospital; songwriting.

A Narrative Approach to Songwriting in a Pediatric Medical Setting: Understanding Caregivers' Lived Experience

Introduction

In a pediatric medical setting, it is essential that children and their caregivers' mental health is supported by mental health care professionals throughout their hospitalization experience, including the transition out of the hospital. This includes dedicated time for parents to process and reflect on their own experience through counseling and expressive therapy. When support for caregivers is neglected, it can affect both caregivers and their children's self-expression and impede opportunities to process their whole hospital experience. Jeffs et al. (2017) found that authentically engaging caregivers throughout their hospitalized family member's care allowed for more support and ease in the transition out of the hospital. Music therapy has a unique ability to convey aspects of the self in both verbal and nonverbal ways. Narrative therapy is based on post-structuralist philosophy which posits that truth is subjective and humans create their own realities (Neukrug, 2018). According to Jørring and Jensen (2018), narrative therapy focuses on altering the relationship between the person and their problem as well as changing the person's narrative about themselves and the problem. This is a collaborative process in which the patient, family, and therapist are co-creators of the therapeutic goals and treatment plan. Both music therapists and narrative therapists come from a place of curiosity and use a variety of creative methods to help clients tell their stories. The basic tenets of music therapy and narrative therapy complement each other due to their client centered and strengths-based nature as well as their holistic view of health. The use of narrative approaches within music therapy could provide new ways for caregivers to express themselves and process their experiences. The goal of this Capstone thesis is to explore ways in which a narrative-informed approach to music therapy can support caregivers in processing their hospitalization experience.

There is relatively little research on the combination of narrative and music therapy approaches, however, of the evidence that exists, researchers have demonstrated the positive effects of each of these approaches on child and caregiver hospitalization experiences. Quiroga et al. (2016) found externalizing conversations with hospitalized children in the context of handicraft interventions to be beneficial in reducing perceived pain, developing positive associations, and decreasing perceived threat of hospitalization. In another study, Baker and colleagues examined how patients in early neurorehabilitation created meaning throughout their hospitalization through self-composed songs (Baker et al., 2018). Regarding caregiver support, Colville (2017) found that the use of Narrative Exposure Therapy (NET) was effective for improving PTSD and anxiety symptoms in traumatized parents in a pediatric medical setting. Narrative Family Therapy (NFT) has also been demonstrated as an effective method for increasing parents perceived sense of agency regarding their child's experience of psychiatric symptoms (Jørring & Jensen, 2018). Within the medical setting, it is paramount that patients do not go through treatment alone, and narrative approaches work to promote communion, or the relationship quality between patients and their caregiver support systems (Rajaei & Jensen, 2019). Family-centered approaches to music therapy have also been seen to promote experiences of joy, acknowledgement of the whole child, and an understanding of the journey and endurance for parents with hospitalized infants (Shoemark & Dearn, 2008). The current literature provides a starting place for a method integrating narrative approaches into music therapy within a pediatric hospital using songwriting and/or music-centered storytelling.

The narrative-informed songwriting approach to music therapy draws from Baker's (2017) research on a group songwriting protocol for caregivers of patients with dementia. Baker's (2017) method involves the co-creation of three songs within a group setting focused on

expressing and reframing negative experiences, celebrating the positive experiences, exploring their evolving role as a caregiver, and identifying healthy coping strategies. The process begins with brainstorming feelings and challenges that come up in caregivers' day to day experience. The therapist then guides a discussion to build insight into these challenges. The final step of the songwriting process involves reading out the words and phrases that the caregivers have come up with and shaping them into lyrics. The proposed narrative-informed approach to songwriting will follow a similar structure starting with caregiver brainstorming words and phrases that come to mind when thinking about their life before, during, and after their child's hospitalization. This will be followed by an insight building discussion leading into lyric and song creation. The result will be a song that encapsulates the intricacies of the caregiver's narrative with respect to their hospital experience.

A qualitative, arts-based research approach will be used to collect and disseminate the data. Viega and Baker (2017) and Gilbertson (2013) demonstrate how the use of arts-based approaches can help researchers gain a deeper understanding of their clinical work. Fox (2018) describes the impact of arts-based research on clarifying his evolving theoretical orientation as well as deepening his understanding of human nature. Developing a narrative-informed music therapy method with caregivers and using an arts-based approach to interpret and reflect on caregivers' lived experience has the potential to impact my growth as a clinician by further deepening my understanding of caregiver experience and clarifying my own theoretical orientation. The results of this exploration also have the potential to impact the support that caregivers in a pediatric medical setting receive in the future.

Literature Review

Caregiver Experience in a Hospital Setting

The experiences of caregivers in hospital settings can be described as fear and anxiety provoking in extremely unpredictable situations. Even more so when the patient is the caregiver's child in need of serious medical treatment such as pulmonary rehabilitation, traumatic injury, serious illness, or major surgery. While this is a wide-spread situation in the United States, little research exists on the perceptions and experiences of caregivers, patients and healthcare providers. The inclusion of a strategic plan to build on the small body of knowledge that already exists, could inform treatment outcomes and transform clinical practice.

Jeffs et al. (2017) conducted an exploratory qualitative study focused on the perceptions and experiences of caregivers, patients, and health care providers during care transitions. Participants were inpatients who had fallen or sustained a fracture and their care team in two acute care hospitals and one orthopedic unit in an urban area in Canada. Interviews were conducted using an open-ended interview format focused on patient and caregiver experience during care transitions, and these interviews were analyzed using a "directed content analysis approach" (Jeffs et al., 2017, p.1444). There were four themes that came out of the analysis, including "watching, being an active care provider, advocating, and navigating the health care system" (Jeffs et al., 2017, p.1446). The theme "watching" reflected active caregiver participation through monitoring the care of their hospitalized family member and the theme "being an active care provider" referred to the responsibility of caregivers providing care that staff would typically take on. Caregivers also reported being actively involved in advocating for their hospitalized family member as well as holding the responsibility of navigating the health care system, which included asking questions about care and coordinating follow-up care (Jeffs

et al., 2017). Overall, there was tension given that caregivers were actively involved in their hospitalized family member's care but were not actively engaged by the health care professionals. Jeffs et al. (2017) recognize a need for reconciling these tensions and addressing the need to actively engage caregivers in their family member's treatment.

In another study, Rennick et al. (2019) sought to understand the lived experiences of parents caring for children with medical complexities in the pediatric intensive care unit (PICU). An inductive approach was conducted, and an interpretive description method was utilized to construct meaning within each caregivers' subjective experience and generate implications for clinical practice. Participants were parents of children in the PICU of a Canadian university-affiliated hospital. Four themes emerged from the data, the first being, "we know our child best" with subthemes of, "living with uncertainty" and "hospital care needs are similar to home care needs" (Rennick et al., 2019, p.4). The second theme was named, "when expertise collides" which described different opinions between parents and health care professionals as well as differences in opinion between health care professionals and their colleagues (Rennick et al., 2019, p.5). The third theme was "negotiating caregiving boundaries" which involved the time-consuming process of building collaboration between caregivers and health care professionals (Rennick et al., 2019, p.6). "The importance of being known" was the fourth theme which caregivers identified as a key part of feeling secure and comfortable in the PICU (Rennick et al., 2019, p.7). Rennick et al. (2019) suggest a focus on improving caregivers' hospital experience by including caregivers in their child's care as soon as possible as well as increasing communication and support between caregivers and medical staff.

Both Jeffs et al. (2017) and Rennick et al. (2019) identified important themes in caregiver experience which come down to the basics of communication, respect, and support for all

members of the care team. It is important to understand the themes that have come to life through previous literature when gathering and analyzing the possible themes that come to life through the implementation of the narrative songwriting method.

Centering Patients and Caregivers in the Therapeutic Process

The importance of communicating with and including the whole family in the treatment process is becoming more of a focus within current literature. Shoemark and Dearn (2008) discuss how parents in a highly technological medical environment struggle to adapt and are often overwhelmed by uncertainty, fear, and grief. Additionally, there has been an increase in literature examining the presence of PTSD symptoms in parents with hospitalized children, specifically parents whose children are in intensive care (Colville, 2017). Given the increase in PTSD symptoms and general stress of caregivers in a pediatric hospital environment, it is even more important that caregivers are supported and placed at the center of their child's treatment.

Shoemark and Dearn (2008) explore the role of family-centered approaches to music therapy with hospitalized infants, which puts the patient and family at the center of care and puts an emphasis on collaboration, empowerment and education. The researchers conducted a narrative analysis of a single case study, and then branched out to writing their own narratives based on their clinical experience working with families with hospitalized infants. Shoemark and Dearn (2008) categorized and lifted themes out of the narratives they wrote, and after taking a break of several months, revisited these themes and re-evaluated them. A colleague who has worked with families with hospitalized infants for 15 years reviewed the narratives and the data for validation of content. The themes that were found included the important characteristics of the music therapist, the triadic relationship in music therapy, the long journey/endurance, joy experienced by parents during music therapy, the acknowledgment of the whole child, the

conditional relationship, and a whole life. These themes support the idea of family members as an integral part of the therapeutic process in a pediatric hospital environment. Music therapists as well as other therapeutic providers can help caregivers connect with their hospitalized child through building on family narratives that support the whole child and family experience.

From the perspective of three family medical therapists, Williams-Reade et al. (2014) followed their passion for narrative therapy by addressing the gaps in the literature around narrative therapy in the medical setting. Williams-Reade et al. (2014) argue that narrative therapy can be a beneficial approach in brief behavioral health encounters by promoting agency and communion for patient and family members. Williams-Reade et al. (2014) propose four core principles that are central to the application of narrative therapy to a brief (10-30 minute) therapeutic encounter in the medical setting. The first principle is to assess and deconstruct the illness experience, the second is externalizing the illness using open ended questions, the third is mapping and evaluating the effects of the illness on the patient and family, and the fourth is reauthoring the illness experience by drawing on unique outcomes to thicken preferred narratives (Williams-Reade et al., 2014). These core principles help the therapist build upon the patients' strengths and support their agency in the treatment process. They also draw upon the resources that the client has in their life, further building communion between the patient and the people in their life.

Much like Williams-Reade et al. (2014), Rajaei and Jensen (2019) expand previous research to promote ways in which narrative therapy can be used in integrated behavioral health care (IBHC) settings to empower patients as experts of their lives and reduce the stigma attached to mental health care. Some of the overarching goals of medical family therapy include promoting the patient and family's personal agency and communion, which are further

strengthened by narrative approaches (Rajaei & Jensen, 2019). Treatment is seen to be more effective when patients are given agency over their treatment goals and process, and narrative therapy holds the patient and family's voice at the center of treatment (Rajai & Jensen, 2019). The process for Rajai and Jensen's (2019) approach to narrative therapy in an IBHC setting begins with joining, which is essentially building a strong therapeutic alliance in a short period of time. The next step is assessment, which involves reviewing patient history, conducting a bio-psycho-social-spiritual interview, and collaborating with parents and other care providers to understand treatment goals and recommendations. Regarding clinical intervention, there are four main narrative interventions used in IBHC settings including: deconstructing problem saturated stories and exploring any meaning behind the patient's illness; externalizing the illness and working towards understanding the patient apart from their illness; exploring the impact of the illness on the patient and family; and reauthoring a preferred narrative (Rajaei & Jensen, 2019). Each of these approaches support the overall goals of building agency and communion through understanding the biological, psychological, social, and spiritual context of the patient and their family. Understanding these intricacies is of crucial importance in a fast-paced treatment setting such as IBHC, and narrative approaches are designed to support patients and families in understanding and rewriting their stories which can help promote a more meaningful hospital experience.

Caregivers' Mental Health

Colville (2017) argues that it is crucial to find ways to support parents' mental health so that they can, in turn, support their children. The present study made a case for the use of NET, which focuses on the integration of multiple traumatic experiences into the client's life narrative. The study took place in a teaching hospital in an inner city in the United Kingdom, and the

treatment was delivered by a clinical psychologist. Participants included four parents with children in the pediatric intensive care unit who had been referred due to meeting criteria for PTSD. There was one father and three mothers in the convenience sample, all identifying as white. PTSD symptoms were measured using the Posttraumatic Diagnostic Scale (PDS) and the Hospital Anxiety and Depression Scale (HADS) was used to measure depression and anxiety. The participants completed pre-treatment and post-treatment questionnaires both 2 and 6 months after completing treatment. The scores were analyzed, and effect size was measured with Cohen's *d*. Results showed significant improvement in PTSD and anxiety symptoms both at 2 months and 6 months post-treatment. At 2 months, the mean scores dropped from 20.75 to 9.25 ($d=1.36$) for PTSD, 14.25 to 8.25 ($d=1.52$) for anxiety, and 5.25 to 3.75 ($d=0.40$) for depression. At 6 months, the mean scores dropped further to 3.67 ($d=2.37$) for PTSD, 5.00 ($d=2.15$) for anxiety, and 1.33 ($d=1.01$) for depression. Parents reported an appreciation for being provided with concrete illustration of their traumatic events at the end of NET treatment. They reported a better understanding of the integration between this traumatic event and other events in their lives as well as an appreciation for the positive moments in their child's hospital stay. Finally, parents reported having a higher tolerance for anxiety provoking situations after NET treatment. The researchers recommend twice weekly NET sessions with parents of hospitalized children in order to see similar positive effects. The sample size was small, and replication of this study on a larger scale is needed in order to further the reliability of this method.

In addition to NET, there has been recent studies of the effectiveness of narrative family therapy (NFT) with children and their families. According to Jørring and Jensen (2018) NFT is grounded in the belief that all members of the family are impacted when a child is suffering from a psychiatric illness, and therefore the entire family needs support. Participants in the qualitative

study were families who were already receiving NFT in the family therapy team at the Capital Region of Denmark. These families were referred due to continued suffering despite receiving usual treatment. Pre- and post-outcome measures for youth ages 8 to 17 were assessed using the Beck Youth Inventory (BYI) to measure symptoms such as anxiety, depression, anger, disruptive behavior, and self-concept. The Parent Activation Measurement (PAM) was used to measure parents' personal agency regarding their child's psychiatric disorder. Data were completed for 48 patients, twenty-eight patients were girls and twenty were boys, and the median age at treatment was 13.2 years. The results showed that there was statistically significant improvement in self-concept ($p=0.002$), depression ($p=0.030$), and disruptive behavior ($p=0.030$) after the NFT intervention. Data showed that changes in psychiatric symptoms were greater than the group as a whole for children suffering within the psychopathological range. This demonstrates that NFT has a positive effect on burdensome psychiatric symptoms. The third finding was that there was a change in activation measurement from pre- to post-therapy for parents with a medium to large effect size. This indicates that parents' perceived sense of agency is positively affected by NFT. Due to the diversity of the participants in the study, the aim was to provide language and ways of placing families in a more powerful position regarding various psychiatric illnesses. Despite relatively small effect sizes in this restricted sample, the researchers' hypothesis that, regardless of diagnosis, NFT can alleviate clinically relevant symptoms was supported. Limitations of this study include the inability to generalize findings due to a lack of randomization or placebo group as well as a decline in the number of surveys filled out by patients. The greatest strength of this study was that it was carried out in a typical clinical setting, and emulated real life where clients and families come with a variety of symptomatology. The researchers recommend that future

research should focus on psychometric evaluations of the effects of NFT to build an evidence base for NFT.

While each of these researchers use a variety of approaches to support caregivers in processing their experience, they all place patients and their caregivers at the center of treatment. This shift towards family-centered treatment is strengthened by music therapy and narrative approaches and offers new methods for supporting caregivers in a hospital setting.

Songwriting and Storytelling to Support Patients and their Caregivers

Therapeutic songwriting and storytelling can be beneficial approaches for caregivers and the children and/or adults that they care for. Songwriting is a creative means of emotional expression and songwriters can address needs related to self-esteem, caregiver identity, and life review by identifying key issues through lyrics (Baker, 2017). This process of creating a song is beneficial in the moment as a release of energy or catharsis, as well as overtime in moments where the song is played again and re-experienced (Baker, 2017). The songwriting process also offers the space for caregivers to reflect on their journeys and look at their experiences from a variety of perspectives (Baker, 2017). Perspective taking and storytelling are key components to narrative therapy and reflecting on one's narrative over time throughout the songwriting process has the potential to encourage a deeper understanding of life events.

Baker (2017) created a songwriting protocol that involved the creation of three songs over the course of 12 music therapy sessions with caregivers of patients with dementia. The songwriting sessions focused on emotional expression, identity exploration, and identification of helpful coping skills. Baker (2017) included a case illustration involving four caregivers (one male and one female spouse, and one son and one daughter) of patients with dementia who were recruited by the manager at the Caledonia Dementia Care in Melbourne. Throughout the

songwriting process caregivers were not only able to accept what they could not change, they also embraced opportunities for positive experiences, such as feeling supported within a group of people with similar experiences (Baker, 2017). Baker (2017) acknowledges that there are aspects of the caregiving experience that are likely consistent across contexts, and therefore this protocol as a whole or in parts could be beneficial for caregivers in a variety of settings.

Baker et al. (2018) conducted a qualitative pilot study examining the process of meaning-making as well as identity reconstruction for patient in early neurorehabilitation. The participants included a total number of 15 adult individuals (male n=11; female n=4) with acquired brain injury or spinal cord injury undergoing inpatient rehabilitation in Melbourne, Australia. Participants in the current study composed three songs, one about their past self, one about their present self, and one about their imagined future self. Semi-structured interviews were conducted with each participant 6 months after completion of the songwriting intervention in which participants were encouraged to reflect on their songwriting experience. The interviews involved listening to each of the participants self-composed songs, followed by a discussion of seven question categories: “What did you mean by the title of this song? What is this song about? Can you tell me about what is the overall message or themes of the song that you were trying to convey? What did you mean by the lyrics in Verse 1, Verse 2, and the Chorus? What were you thinking about when you wrote this song? How does it feel to listen to this song now? Do you think the feelings have changed from when you wrote them? Does this song still have meaning for you now? Why/why not?” (Baker et al., 2018, p.3-4). The interviews were transcribed and imported into MAXQDA qualitative analysis software for coding and analysis. After two of the researchers independently analyzed the interviews, they came together to find common themes and group participants’ stories based on similar journeys through the songwriting process. There

were four journeys that were lifted out of the analysis: “1) re-conceptualizing values and shifting perspectives about self; 2) recognizing acquired inner resources to negotiate discrepancies in self; 3) confirming existing values and identifying resources and coping strategies; and 4) confirming previously held values and ongoing process of negotiating discrepancies in self” (Baker et al., 2018, p.4). These journeys demonstrate the complexity of the evolution of self-concept post-injury and make a case for the use of therapeutic songwriting to explore and reconceptualize the self.

Songwriting in a Global Pandemic

Akard et al. (2021) created a protocol for examining the efficacy and feasibility of a songwriting intervention for cognitively impaired children ages 5-17 who are receiving complex or palliative care by their caregivers. Akard et al. (2021) hypothesized that their family-centered songwriting intervention would be feasible and demonstrate positive effects towards child, parent, and overall family outcomes. The population of this study will include 25 child-parent dyads, where parents are 18 years of age or older and are the child's primary and secondary caregivers. The study design is a one group pre- and post-test, repeated measures, clinical trial design and data will be collected at baseline, one week post intervention, and within one month or after the death of a child. Board-certified music therapists will deliver the songwriting intervention that includes 4 weekly sessions with child-parent dyads focused on caregivers creating songs about their children. This study was initially designed for in-person delivery but was moved to remote delivery due to the COVID-19 pandemic. The intended outcomes measured include an analysis of treatment fidelity for each session, child satisfaction and psychological distress, parent satisfaction and psychological distress, and the family environment. This preliminary design for the exploration of the feasibility and efficacy of

family-centered music therapy for cognitively impaired children and their caregivers is helpful for informing the songwriting method in this thesis, specifically the length of treatment, methods utilized, and data collection process.

Quiroga et al. (2016) conducted a qualitative study that explored the effects of digital and handicraft narrative interventions on negative consequences of hospitalization in a pediatric setting. Participants were 44 pediatric patients (22 boys and 22 girls) between the ages of five and twelve years from four hospitals in Monterrey, Mexico. The reasons for hospitalization included gastroenteritis, trauma, and respiratory problems, none of which were chronic. Participants were randomly assigned to one of two narrative-based individual interventions including digital activities (DA) and handicraft activities (HA). In both interventions, participants were asked to draw their pain and make a collage. The collage included people and things that had helped them during their hospitalization and any activities the participants wanted to do when the pain was gone. The participants were then told a story about a fictional patient who was visited by a doctor with the goal of understanding his/her pain/discomfort. The researchers then asked the patients to draw what their pain was doing in their body and then imagine what their own pain would *like* to do and give the pain a name. Participants were then given a strategy for dealing with their pain and asked about what had been helpful during their hospital stay. Quiroga et al. (2016) applied an inductive reasoning process to condense raw data into themes and categories. Results demonstrated that drawing the pain, talking about the pain as a separate entity, naming the pain, and stressing the difference between themselves and the pain were all influenced by externalizing conversations. Drawing was seen as a key element in giving the patients a window to view their pain through and helped researchers gain an understanding of the patients' understanding of their pain. The collage process was helpful for integrating and

reflecting on the patients' hospitalization experience and provided a physical symbol of their knowledge and learning. Overall, researchers identified that both HA and DA were successful in reducing perceived pain, developing positive associations, and decreasing the perceived threat of hospitalization. While the intent of this qualitative study was not to generalize findings, this research provides important information for ways to communicate with patients outside of the traditional medical model using approaches such as art and storytelling that do not necessarily have to involve words.

Arts-Based Research, Song-writing, and Lived Experiences

Arts-based research (ABR) by music therapists has been used in a variety of contexts to provide researched with a more self-reflective and creative means of exploring their topic of choice. Viega and Baker (2017) present current literature examining the impact of therapeutic songwriting to support well-being in a variety of patient populations. Viega and Baker (2017) acknowledge their own clinical perspectives, with Baker focusing predominantly on outcome-oriented approaches with a more recent shift towards constructing identity through songwriting, and Viega identifying as a context-oriented and music-centered music therapist focused on dynamic musical relationships. The songs examined in this study were from a previous study focused on understanding the self-concept of people with spinal cord or acquired brain injury currently in rehabilitation through the songwriting process. The participants created three songs over the course of 12 sessions focused on the past self, the present self, and the imagined future self. One participant, a 20-year-old woman names Ashley with a spinal cord injury, was selected and Baker analyzed the lyrics of the songs using a deductive analytical approach focusing on the domains of self (personal, social, family, moral, physical, and academic), as well as an analysis of the music recordings. Viega used and arts-based research approach in his analysis of Ashley's

songs which involved open listening, documenting affective and intuitive responses to the music including physical sensations, and sampling and remixing the three songs. The outcome of the remix was a single song to represent Ashley's developmental and psychological journey. Both approaches go about the process of examining and reflecting on Ashley's songs in very different ways; however, they reveal similar insights. In this study, an experiential arts-based approach allowed for the researcher to explore an embodied understanding of the complexities of losing your sense of self. Overall, combining these approaches allowed for a more holistic narrative of Ashley's development through songwriting. Limitations of utilizing experiential arts-based approaches in combination with deductive approaches include the feasibility due to the time-consuming nature of these approaches. Another factor is the training and supervision required for the in-depth responses in experiential analysis. Lastly, when using analytic and experiential approaches, countertransference can arise and bring forth interpretations that are not necessarily congruent with the person in therapy. This can open the door for clinical interventions and meaning making but can also be damaging within the therapeutic relationship. Further research builds upon the use of ABR to examine countertransference in order for researchers to gain a deeper understanding of human experience.

Fox (2018) uses a qualitative, heuristic, arts-based model of research to describe his own experience with songwriting, and in doing so, makes a case for arts-based research methodology. For Fox (2018), arts-based research has increased clarity in his theoretical orientation and facilitated a deeper understanding of his own personal experience in relation to human experience. Arts-based research makes different assumptions than qualitative or quantitative research in that data is revealed through images rather than through external measurements or interviews (Fox, 2018). This demonstrates that bias occurs within human subjects, the

experimenter and the images themselves. Arts-based inquiry is guided by the art itself and brings forth aspects of the work that were previously unknown (Fox, 2018). This is particularly applicable to narrative research in that each client brings a unique personal narrative that, much like a form of art, conveys aspects previously unknown. Fox (2018) offers helpful guidelines for engaging in arts-based inquiry such as staying with the image, practicing maleficence and beneficence, allowing image autonomy, and proceeding as an artist would. These guidelines are essential for focusing and deepening the arts-based process. Arts-based practice, according to Fox (2018), heightens our awareness of unconscious material in a non-judgmental way in order to achieve wholeness, which is imperative when reflecting on other's lived experience in hopes to gain a deeper understanding.

Gilbertson (2013) presents a long-term repeated-immersion research process exploring how qualitative and arts-based methods can help identify the meaning of different therapeutic interventions within music therapy. The start of this doctoral research project was an explorative narrative analysis that looked at any links between music improvisation and clinical change during the rehabilitation process. This involved reviewing and analyzing video and audio archives of music therapy sessions and took a close look at "Episode 1" from a session with Bert, patient recovering from a traumatic brain injury (TBI). The narrative analysis of "Episode 1" included a musicological transcription and analysis, frequencies and dynamics captured through a sonograph, and a narrative text created from the clinical notes taken at the time of therapy. Throughout the analysis, isolation and minimal contact during the process of neurorehabilitation were common themes that became apparent. The author discussed the evolution of how he conceptualized the case over time and the need to reconsider and evaluate the case from a more integrative perspective including the patient's family as well as the nature of the therapist's own

decisions. This resulted in the author's engagement in an expressive writing arts-based reflection in which he wrote a letter apologizing to Bert's mother for not including her in Bert's early music therapy treatment. The reframing and recontextualizing of Episode 1 through the author's expressive writing process allowed him to acknowledge the importance of the interpersonal and social context of individuals with TBI and the people in their lives affected by the injury. This new understanding of the original case study communicates a need for considering a social basis for music therapy in early neurorehabilitation rather than individualized conceptualizations of capabilities and functions. After further analysis of the video footage, the author realized the absence of his body limited the understanding of the meaning behind the therapeutic interaction. The author then furthered this arts-based research to focus on the embodiment of music therapists working in areas of health and well-being. This involved the creation of body molds of the hands of music therapists as well as semi structured interviews followed by a written interview. The analysis demonstrated that the researcher's body could be considered the main way of relating to the client, and that it could make sense to use the parts of his body that are most extensively trained in the relating process. The researcher illuminates a key finding, in that considering the visual, auditory, and embodied material within music therapy can bring up new realizations about the meaning of our bodies both individually and socially.

The purpose of using arts-based research to analyze and reflect on the data presented in this thesis is to deepen my understanding of the holistic, lived experience of caregivers of hospitalized children. Viega and Baker (2017), Fox (2018), and Gilbertson (2013) all communicate the ways that arts-based research can enhance the personal reflection of the researchers in relation to the research subject and uncover unknown areas within the research process. This aspect of research is a key component of understanding and interpreting themes of

caregiver experience and will allow the research to more authentically communicate any findings.

This exploratory project focused on understanding caregivers' lived experience so that future music therapists and counselors can best support their needs. In light of ABR in gaining a deeper understanding of human experience, I will not only be lifting out the main themes that caregivers identify through their experience, I will also be reflecting on my own experience throughout this project. Through combining the songwriting process with written and music-based reflections, the final narrative synthesis is intended to pave a path for future music therapists to be able to support caregivers dealing with the fear and anxiety of unpredictable situations.

Method

Participants

The participants in this exploratory thesis project included two caregivers (a mother and father) of one of the patients on the medical units of a Children's Hospital in the metro Boston area. Participants whose children were already receiving music therapy were invited to participate in the present thesis project, and participation was voluntary. Participants took part in a four-phase songwriting process focused on their hospital experience. Caregivers were informed that no protected information will be shared in the research process, and that they are welcome to discontinue the sessions at any point in the process. Sessions were family-centered and included all family members who wished to be part of the songwriting process.

Materials

All phases required a pen and paper to take notes and make drafts for the songwriting process. Phase two required instruments including the guitar. Phase three required a device to record the song along with the guitar.

Procedure

Sessions took place in the hospital room of caregivers' child given the need for caregivers to constantly be attending to their child's needs. Sessions took place once per week for 30-45 minutes. Due to the nature of the population and the dynamics of a pediatric hospital, the flexibility to expand the songwriting process was explored to establish a frequency of sessions that can be suggested as treatment as usual.

The four-phase model and songwriting procedure was inspired by the work of Baker (2017), Baker et al. (2018) and Akard et al. (2021) who have conducted numerous studies involving songwriting with caregivers. This was a qualitative iterative arts-based procedure that

focused on supporting caregivers in creating a song that most closely relates to and reflects their experience in a pediatric hospital setting.

Phase One

The first phase of this exploratory project included rapport building and reflecting on caregiver's overall hospitalization experience. Information about family history, the hospitalization journey, important cultural considerations, and the caregivers' relationship with music was discussed. This included a brainstorm of any words or phrases that came to mind for the caregivers when reflecting on their time in the hospital.

Phase Two

The second phase was focused on a songwriting process to support caregivers in externalizing their hospital narratives through music. This included both verbal and non-verbal/instrumental based expression of their hospital journey. Caregivers were assisted by the researcher in constructing lyrics based on the words and phrases that came to mind during Phase One. The researcher used the guitar to provide options of chords for caregivers to choose from to find an instrumental background that fit the mood of their lyrics.

Phase Three

In the third phase, the caregivers were given the option of recording the song and/or sharing the song with important people in their lives.

Phase Four

The fourth phase involved termination, which included a brief interview where caregivers were asked what the process of creating a song based on their hospital experience was like.

Data Collection

Data consisted of journal entries and violin improvisations completed by the researcher after each session. First, a written narrative of the session was recorded including what took place during the session as well as the researcher's subjective experience of the session. This narrative journal entry contained unfiltered information based on what was brought up within each session, which was stored in a locked filing cabinet and is not included in the final study. The researcher also created violin improvisations focused on the main themes and feelings that were present in each session. The improvisations were recorded and played back by the researcher for reflection. The researcher then engaged in listening to the improvisation and journaled about what was heard in the music including any self-reflections. Each of these journal entries and musical reflections took place after each session and on the same day as the session. Once all four phases were complete, the journal entries were analyzed by extrapolating main themes and meaning units across the content of each session as well as themes present in the violin improvisations. Finally, meaning units and themes were organized and frequency charts were created based on how often each theme was mentioned in the journal after each session and journal reflection of the violin improvisation. The process of lifting out meaning units and themes follows a similar process as seen in Forinash's (1992) phenomenological research analysis which takes a deeper look at narratives to derive meaning units.

Results

After the journal entries and musical reflections for each session were analyzed, there were 24 themes/meaning units which emerged. See a visual representation of all themes presented in the Appendix A. While many of these themes are important to the overall conceptualization of caregivers' hospital experience, the analysis focused on four of the most frequently occurring themes in detail while acknowledging the additional themes with more brevity. The top four themes included: Everything at once/Overwhelm; A moment of calm; Music as containing/supportive; and Connection through music.

Figure 1

Illustration of the frequency of the top four themes across all sessions.

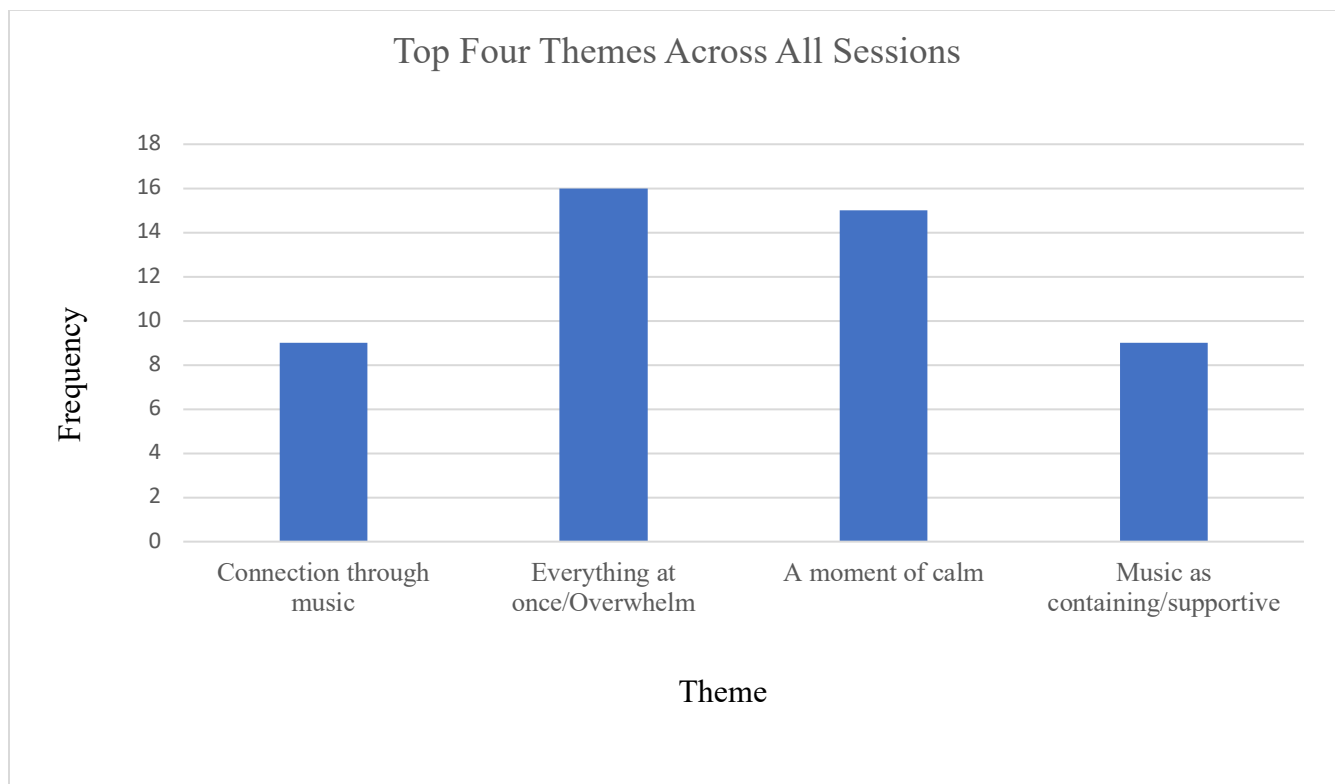
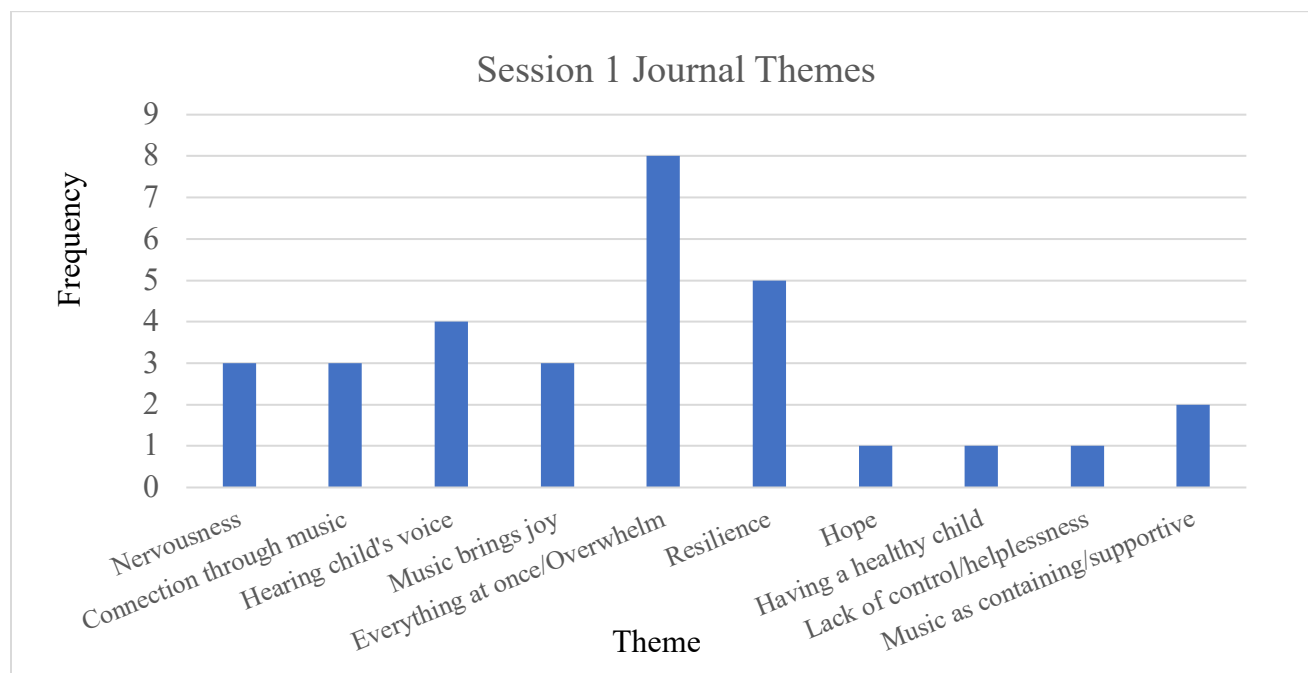


Figure 2

Frequency of themes present in journal entry from session One

**Figure 3**

Frequency of themes present in musical reflection from session One

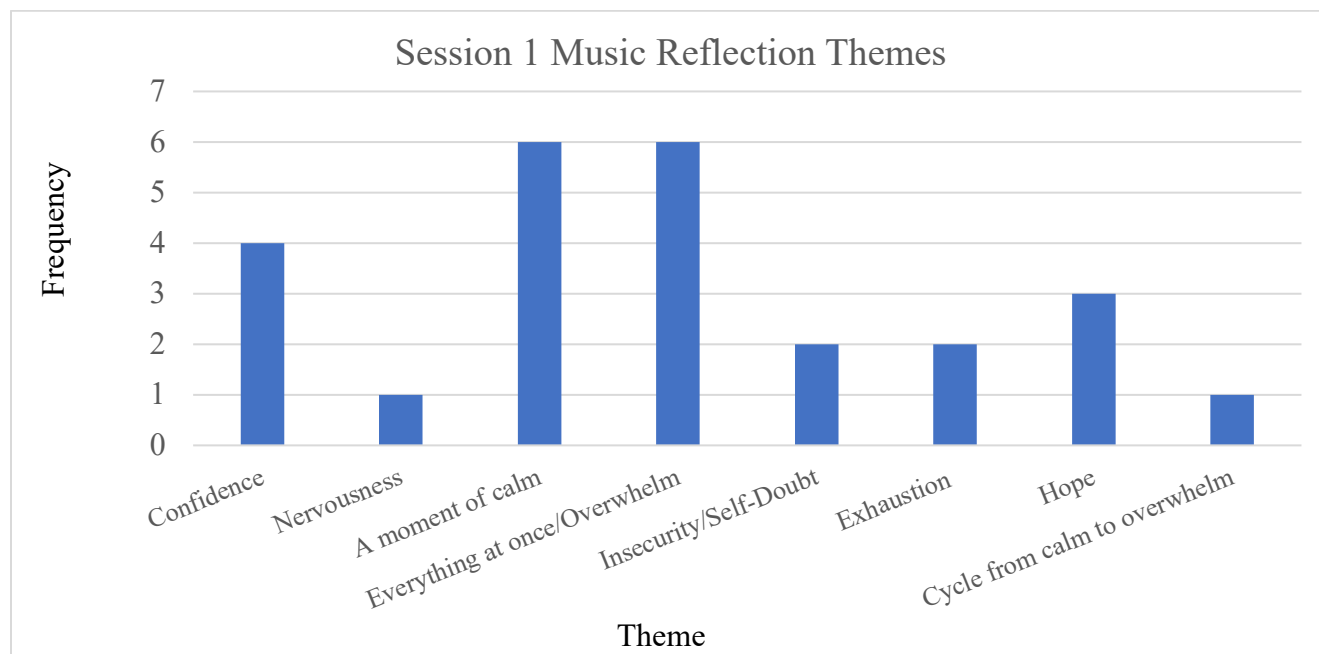
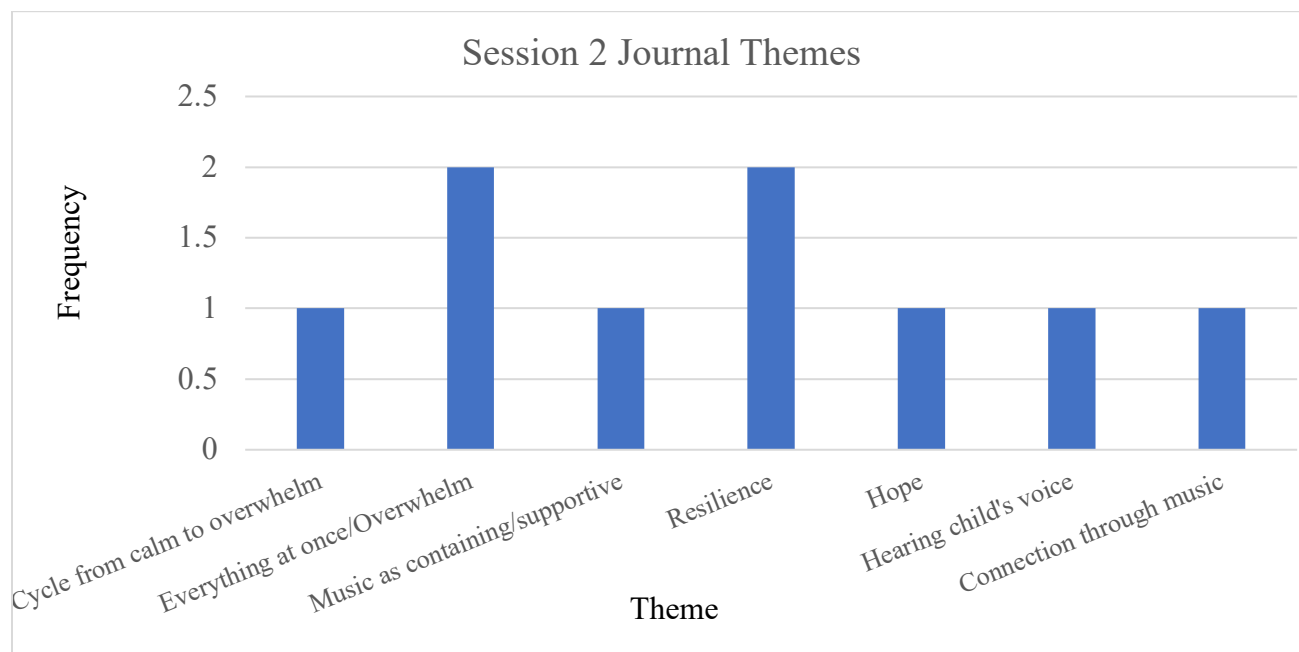


Figure 4

Frequency of themes present in journal entry from session Two

**Figure 5**

Frequency of themes present in musical reflection from session Two

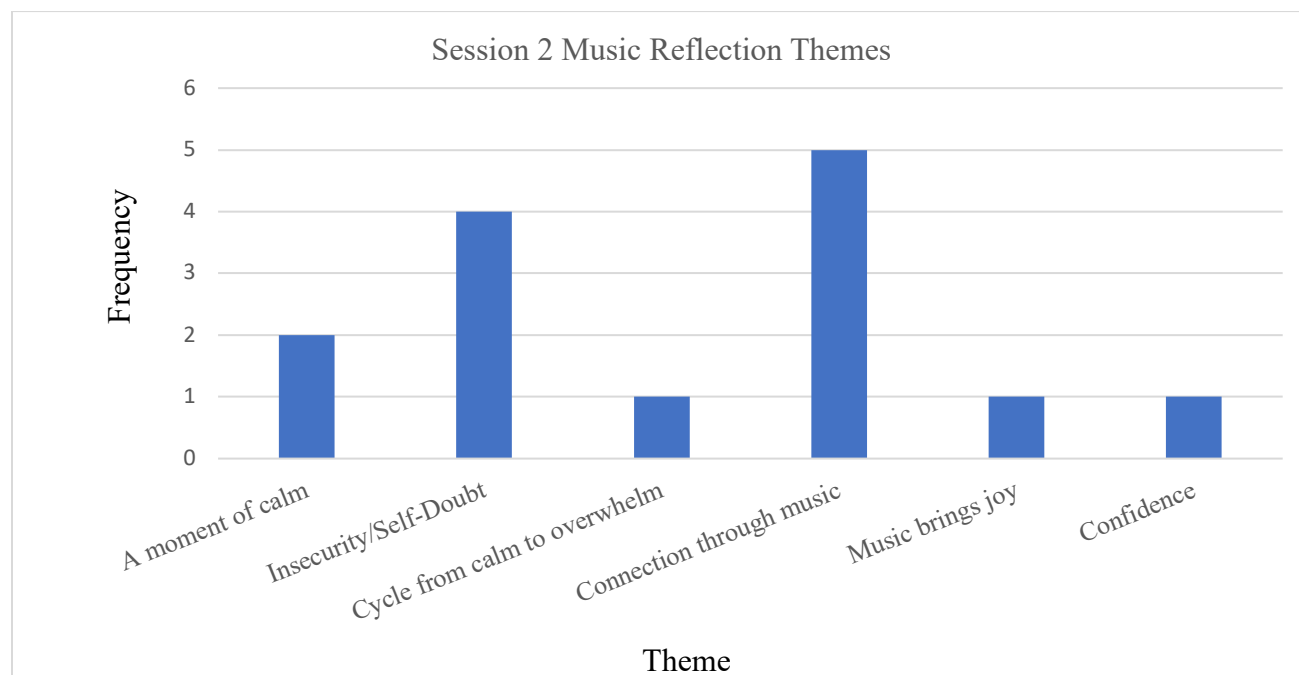
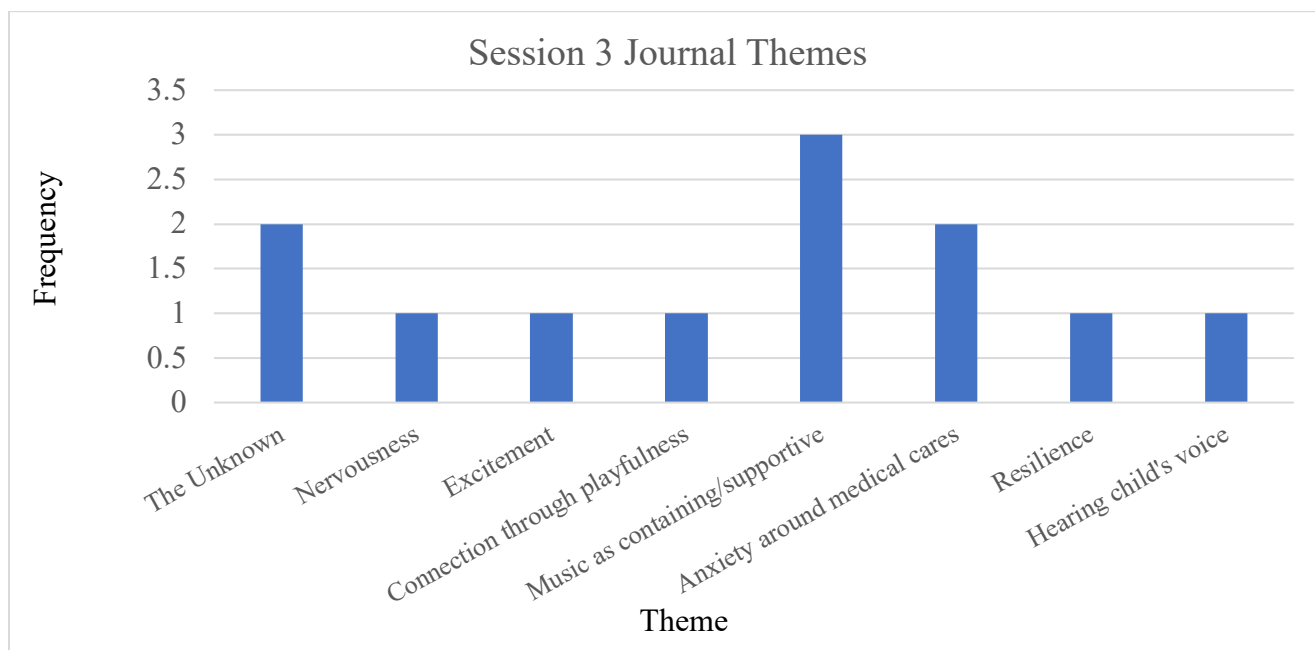


Figure 6

Frequency of themes present in journal entry from session Three

**Figure 7**

Frequency of themes present in musical reflection from session Three

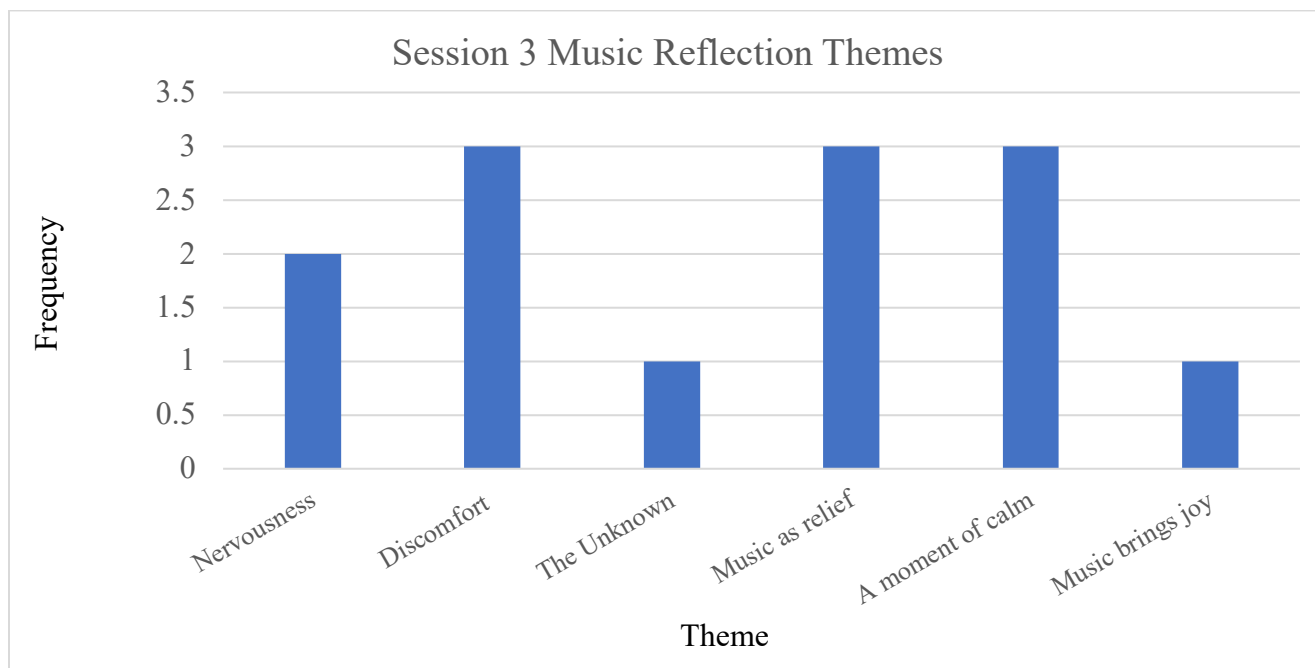
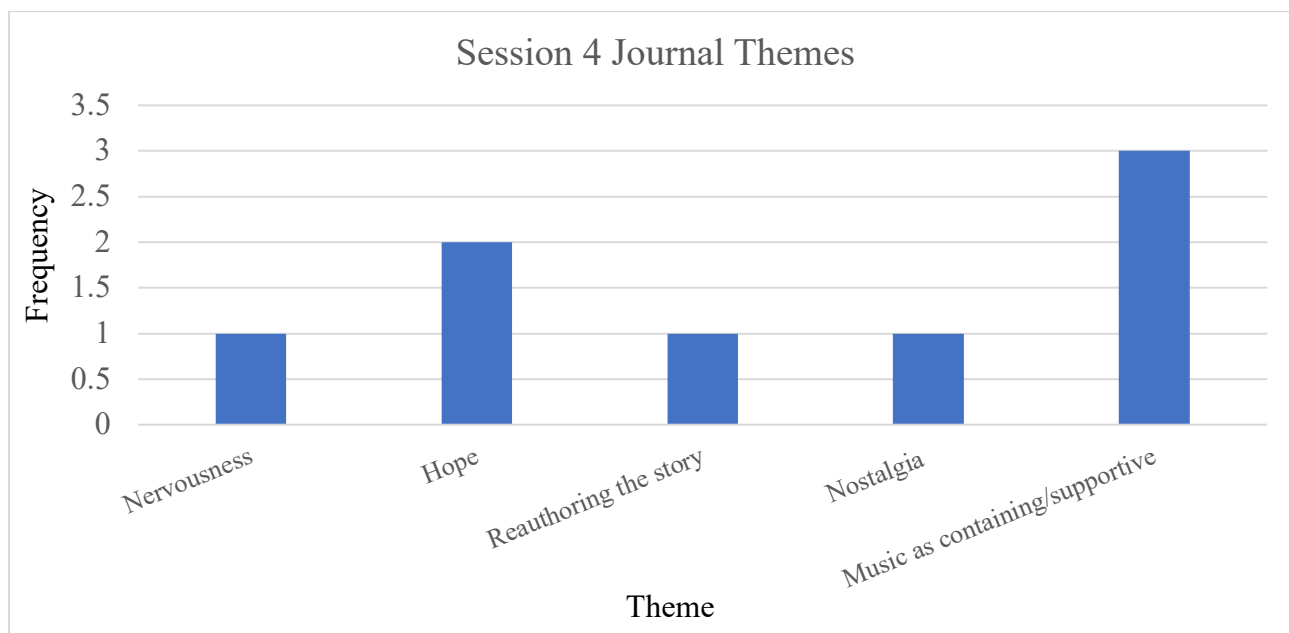
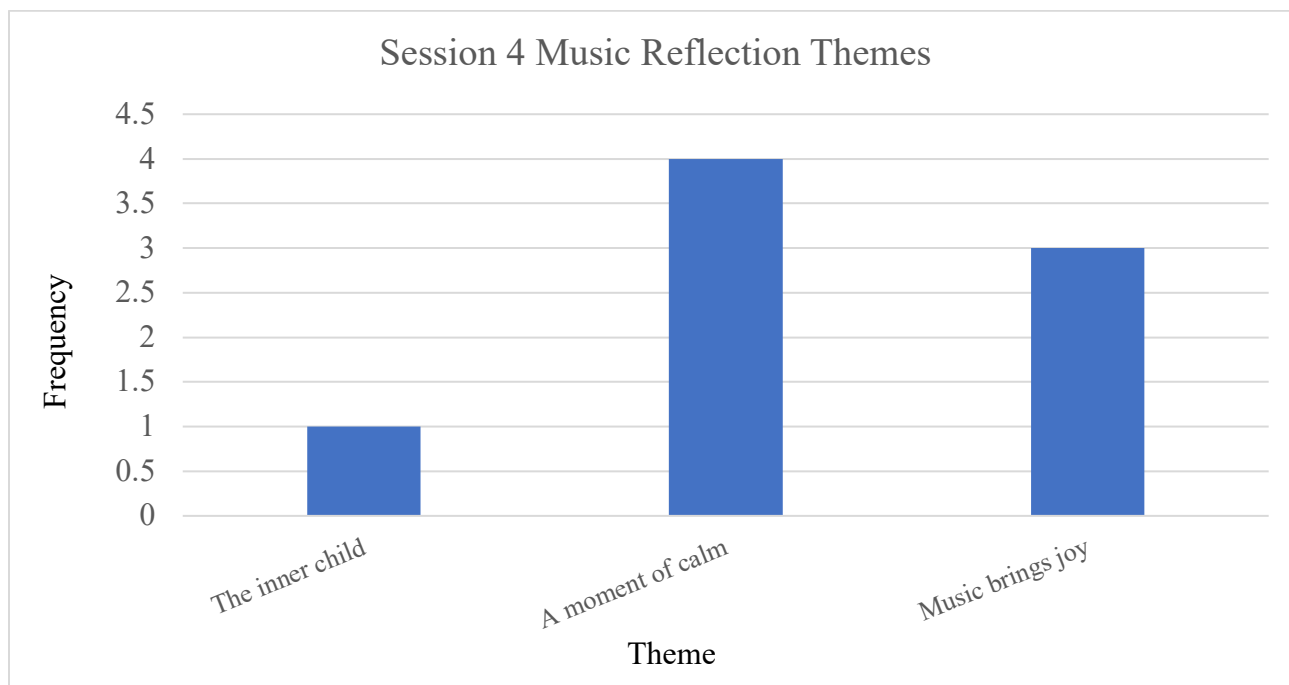


Figure 8

Frequency of themes present in journal entry from session Four

**Figure 9**

Frequency of themes present in musical reflection from session Four



Discussion

Everything at once/Overwhelm

Previous research has demonstrated the overwhelm and PTSD symptoms that often come with being in an artificial and unpredictable hospital environment (Shoemark & Dearn, 2008; Colville, 2017). The theme *Everything at once/Overwhelm* surfaced over the course of all four sessions and was the most frequent theme. This theme represents the overwhelming nature of having a child in the hospital with constant changes in the child's needs and many different providers attending to these needs. This often resulted in a sudden surge of people entering the hospital room with a variety of agendas. Caregivers experience the overwhelm of managing their child's needs, attending to every beep and alarm, answering difficult questions about their child's care, attending caregiver teaching sessions, and comforting their child emotionally during difficult procedures. Each of these tasks is difficult on its own and it can become extremely overwhelming when these tasks overlap.

Across the four songwriting sessions, I was witness to this theme repeatedly. I would often enter the room and it was clear that there had just been a period of *Everything at once/Overwhelm*, and other times these moments would surface in the midst of the songwriting session. During the times when I was present for these moments, I felt a sense of intense emotional overwhelm. This is represented in my reflective journaling based on my violin improvisation from session one in which I wrote, "Chaotic trilling brings up an overwhelming feeling of disorganization. Doubt. Feeling out of place and unsure of where to go". In this moment of reflection, the trilling in the violin accurately portrayed my emotions related to this theme in a way that words could not.

A Moment of Calm

The second most frequent theme was *A moment of calm*. This theme was prevalent across all four sessions as well and can be thought of as the moment of lull before an intense storm comes through. This was experienced on many levels throughout the four sessions and was either witnessed and experienced by me and the caregiver or was discussed in the context of the songwriting process. This theme is connected to the theme of *Everything at once/Overwhelm* in that *A moment of calm* can precede or follow the overwhelm.

It was during *A moment of calm* that the songwriting process was best supported. These moments provided space for the caregivers to reflect without as many distractions but were also few and far between. Across all four sessions the experiences of *A moment of calm* were fleeting and almost too short for the caregivers to fully enter the songwriting experience fully. The use of the word “moment” is meaningful in this sense and conveys how brief the periods of calm are for caregivers in a pediatric hospital. This is further reflected in the violin improvisations by the back and forth between stable melodic lines and more intense fast-paced melodies. The calm feeling that comes through the violin is often followed by a more frantic and out of control musical interlude and reflects this cycle.

Music as Containing/Supportive

There were many moments across the four sessions where music acted as a containing and supportive force. Williams-Reade et al. (2014) and Rajaei and Jensen (2019) discuss the use of narrative approaches to promote caregiver agency and center caregivers at the heart of treatment. This narrative songwriting process created authentic spaces where caregivers could process their hospital experience in a contained and supported way. The supportive role that music played was seen during times of overwhelm such as during impromptu medical cares, as

well as moments of calm where caregivers were in a more reflective mental space. The music itself was seen to contain and support the process of forming lyrics and helped welcome the caregivers into the songwriting space and center their experience.

The most common moments of *Music as containing/supportive* occurred during moments of overwhelm. Given the nature of the hospital environment, there were frequent moments of interruption by medical providers and moments where the caregivers needed to put everything aside and attend to their child. This was all part of the caregivers' overall hospital experience, and I began to see my role as providing containing/supportive music to ease these rapid transitions in and out of the songwriting process. In using the music to create smoother transitions within a chaotic hospital environment there appeared to be more comfort and engagement in the songwriting process from the caregivers. Rather than being jolted from one extreme to another, the music acted as a bridge that communicated acceptance of the cognitive shift between urgent and unexpected medical cares to the reflective songwriting process.

Connection through Music

Over the course of four sessions, there was a clear sense of *Connection through music*. This theme surfaced in many ways including connection between caregivers and the music, connection between myself and the music, as well as connection between myself, the caregiver, and the music. Each of these components of this triadic relationship is described in detail below.

Connection between the caregivers and the music

Music was seen as a connecting force for the caregivers and their family. Throughout the four sessions, the songwriting process brought up memories and discussions of the role that music plays in the lives of the caregivers and their children. The songwriting process itself was used to identify and process the caregiver's feelings and connect them to their overall hospital

experience. Much like Quiroga et al. (2016) found in their study of narrative handicraft interventions in a pediatric hospital, the arts-based process allowed for nonverbal connection and emotional expression outside of the traditional medical model. I witnessed moments of connection between the caregivers and their child through music, and the role that the songwriting process played in reflecting on the caregiver/child relationship.

Connection between myself and the music

Fox (2018) discussed the heightened awareness of unconscious material that arts-based research often brings to the surface. As I witnessed moments of connection between the caregivers and the music, *I* became more connected to the music. This connection strengthened each time I provided containing/supportive music during moments of transition because I needed to be in tune with the present emotions of the caregivers and patient in order to meet them where they were and match the music to their experience. Much like Fox (2018) and Viega and Baker (2017) discovered in their research, I found that engaging in my own reflections through musical improvisation allowed more space for the examination of countertransference and the ways in which my thoughts and feelings reflected those of the caregivers.

Connection between myself, the caregivers, and the music

Engaging in an iterative arts-based process throughout the songwriting process with caregivers further deepened the connection between myself and the caregivers and allowed a more holistic approach to data analysis. This builds upon the work of Viega and Baker (2017) and others who advocate for the use of arts-based research to access a more embodied approach to data collection and interpretation. Music acted as a connecting bridge between myself and the caregivers, as seen in my journal reflection on the violin improvisation from session two:

As soon as we started playing music together to search for the right mood for the song, the nervousness dissipated and the connection between myself and the parent strengthened. As we continued, the flow continued to get stronger and as the parent and I began formulating lyrics I felt even closer to her story and the feelings she had built up within her.

This is a clear example of the way that the music helped connect me to the mother's experience and more deeply understand her narrative. As both caregivers and I worked together to put their experience into words, I felt the therapeutic alliance strengthen and allow me to empathize with their experience. My connection to the music throughout each session, from lyric creation to supportive interlude, allowed me to experience the hospital environment more deeply as if I was seeing it through their eyes.

Additional Themes

There were many important themes that were lifted from the caregivers' narratives and reflected in the violin improvisations, and while I chose to focus on the four most referenced themes this does not mean that the other themes are less important to the caregivers' hospital experience. For instance, there are themes from my own experience including *Nervousness*, *The Unknown*, *Insecurity/Self-Doubt* and *Discomfort*. These themes are related to being new to the field of music therapy and counseling, which comes with a great deal of insecurity and self-doubt with reference to clinical work. Across the four sessions, I experienced this as nervousness and discomfort, which become less prevalent themes later on in the sessions (see Appendix A).

There were also additional themes related to the caregivers' hospital experience such as *Hearing child's voice*, *Music brings joy*, *Resilience*, *Hope*, *Confidence*, *Having a healthy child*, *Lack of control/helplessness*, *Exhaustion*, *Cycle from calm to overwhelm*, *Excitement*,

Connection through playfulness, Anxiety around medical cares, Music as relief, Reauthoring the story, Nostalgia, and The inner child. These themes were referenced less frequently in the data and reinforce the top four most frequent themes. Of note, the themes such as *Hearing child's voice, Music brings joy, and Connection through playfulness* all appeared to play a role in strengthening the caregivers' confidence and resilience. Fully exploring and understanding these additional themes is important in understanding caregivers' hospital experience; however, that is outside of the scope of this exploratory thesis project and additional research is necessary.

Implications

This exploratory Capstone thesis used a narrative-informed approach to music therapy to understand the lived experience of caregivers of children in a pediatric hospital. Specifically, a narrative-informed songwriting intervention was carried out with the parents (a mother and father) of one patient at a Children's Hospital in the Boston metro area. Previous research calls for increased opportunities for caregivers to authentically engage in their own processing of their hospital experience and identifies possible narrative and arts-based methods for engaging caregivers in this process (Jeffs et al., 2017; Rennick et al., 2019). The results of this research indicate that a narrative-informed approach to songwriting has the potential to lift out meaningful themes that allow music therapists and mental health professionals to better understand the lived experience of caregivers.

This narrative-informed songwriting process has the potential to positively impact the support that caregivers in a pediatric medical setting receive in the future as well as the approach that music therapists take when working with caregivers. Providing a space for caregivers to process their narratives through music can support the caregivers' own reflection and understanding of life events, and simultaneously strengthen the therapeutic relationship. It is

recommended that future research focus on narrative-informed songwriting approaches with a larger sample of caregivers in pediatric hospital settings in order to explore this initial study further. Additional research could demonstrate the need for hospitals to provide clinical support to caregivers in a pediatric hospital setting.

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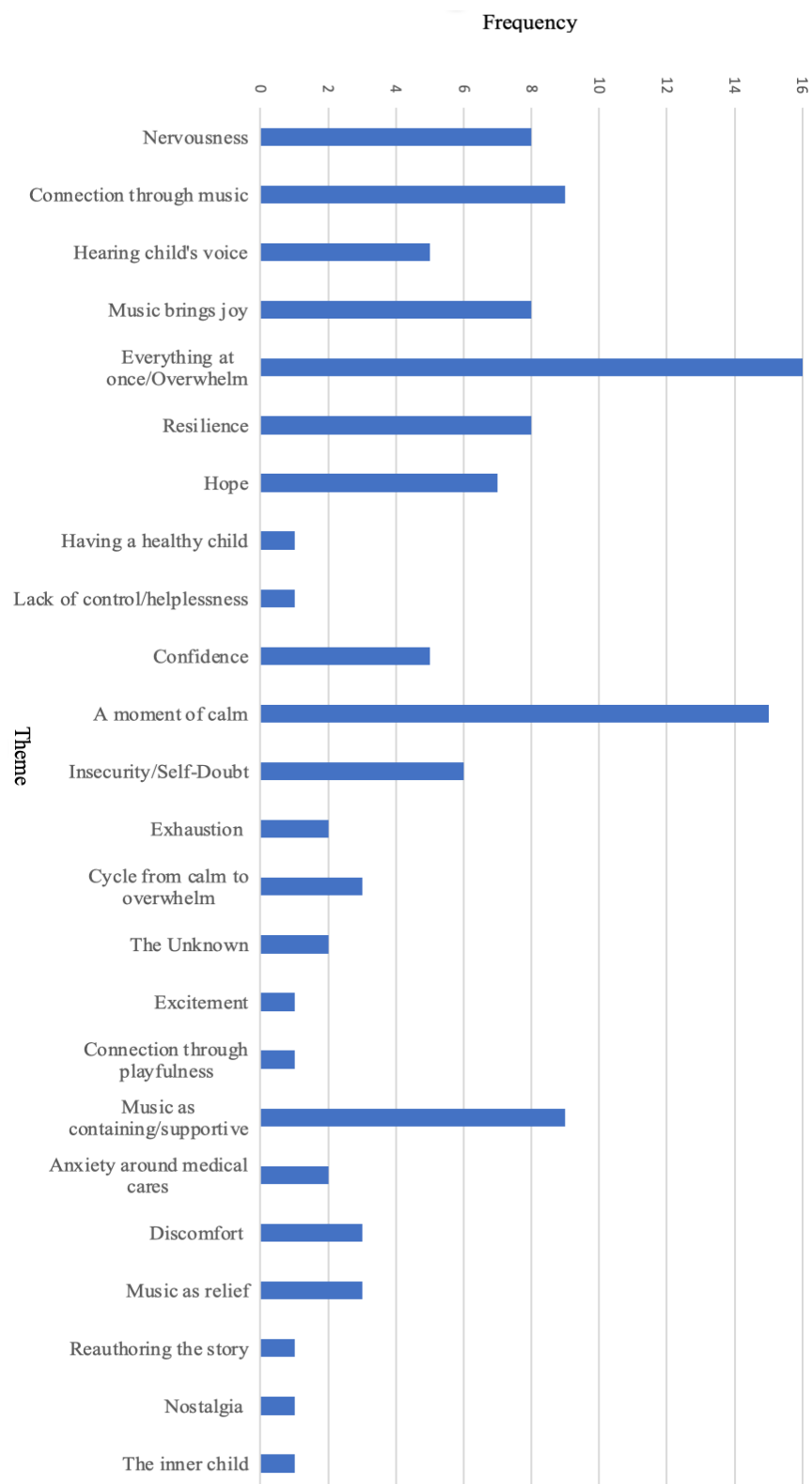
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Appendix A

Theme Frequency Across All Sessions



Appendix B

Audio File 1

Violin Improvisation Reflecting on Session 1.



Audio File 2

Violin Improvisation Reflecting on Session 2



Audio File 3

Violin Improvisation Reflecting on Session 3



Audio File 4

Violin Improvisation Reflecting on Session 4



THESIS APPROVAL FORM**Lesley University****Graduate School of Arts & Social Sciences****Expressive Therapies Division****Master of Arts in Clinical Mental Health Counseling: Music Therapy, MA****Student's Name:** Izabella Lidrbauch**Type of Project:** Thesis**Title:** A Narrative Approach to Songwriting in a Pediatric Medical Setting:
Understanding Caregivers' Lived Experience through Development of a Method**Date of Graduation:** *May 21st 2022*

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: *Dr. Rebecca Zarate*