Spring 5-21-2022

Moving Through Loss: The Experience of Ambiguous Loss with Hospitalized Children, The Development of a Method

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Capstone Thesis

Lesley University

May 5, 2022

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Specialization: Dance/Movement Therapy

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Abstract

The current method examined the effects of ambiguous loss with medical transplant patients in a pediatric hospital by utilizing a dance/movement therapy intervention. The development of this method was based on ambiguous loss theory with a dance/movement therapy approach. The explored literature identified central themes of ambiguous loss, such as resilience. These themes were connected to the practice of dance/movement therapy, such as embodiment. With this connection, the intervention was developed and implemented with participants. The central themes that emerged from the intervention were change, loss, meaning-making, and hope. One child and two adolescents were participants in this intervention, and each was treated as a separate, individual intervention. All three of the participants had or were awaiting a form of transplant. By utilizing a dance/movement therapy method, the participant embodied an experience that is often difficult to find words to describe. The intervention included a verbal check-in, body-based warm-up, a movement directive, a movement-based closing, and a verbal closing. Rich and positive results were produced by this method that provided a deeper understanding of ambiguous loss with chronically hospitalized children. The recognition of ambiguous loss within the medical and mental health field will provide patients with further, invaluable support throughout their hospitalization.

Keywords: ambiguous loss, dance/movement therapy, pediatric hospitalization, meaning-making

Author Identity Statement: This author identifies as a straight, cis-gendered, White woman from the Southern United Stated with mixed European ancestry.

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Introduction

"Each of us carries a unique spark of the divine, and each of us is also an inseparable part of the web of life."

- Viktor E. Frankl,

The term ambiguous is defined as something unclear, obscure, or able to be understood in more than one way (Merriam-Webster Dictionary, 2021). Ambiguity can be experienced in many facets of our lives and is often hard to describe. Loss is just one experience that may promote feelings of ambiguity. Loss is embedded in human existence, for better or for worse. Hospitalized children and their families in a pediatric hospital setting experience loss, and all its ambiguities, on a daily basis.

Ambiguous loss, a term first coined by Pauline Boss, refers to a loss that is unclear, traumatic, externally caused, and confusing (Boss, 2010). Two categories, or experiences, of ambiguous loss, have been presented to help clarify this term. The first type occurs when a support system or family views someone as "physically absent but psychologically present because it is unclear whether they are dead or alive." In contrast, the second type is the opposite experience; they are physically present but psychologically absent (Boss, 1999, p 8).

When relating to children's experience in a pediatric hospital, ambiguous loss occurs where someone may be physically present but absent in other areas. For example, a patient who is prescribed a significant amount of medication for pain management may not be present psychologically. Alternatively, a patient who is intubated may not be fully awake. However, this type of loss is complex and not limited to someone being simply psychologically absent. The

setting and procedure of the hospital system can create obscurity for the patients and their families. In addition, the diagnostic tests can create an emotional rollercoaster, whereas a precise diagnosis can create confusion around the quality of life ahead (Boss & Couden, 2002). For example, patients awaiting a cancer prognosis or a transplant donor may feel unclear on how to move forward.

Dance/movement therapy (DMT) was the primary intervention used in this method. This project included the design and development of a method, which included a DMT intervention conducted during individual sessions. The participants in this method were three medical transplant patients at a pediatric hospital who had experienced chronic or long-term hospitalization. This method will help inform fellow clinicians on the use of dance/movement therapy in a pediatric hospital in relation to ambiguous loss.

Dance/movement therapy is defined as "the psychotherapeutic use of movement to promote emotional, social, cognitive, and physical integration of the individual, for the purpose of improving health and well-being" (ADTA, 2022). While a study has not been conducted on utilizing DMT specifically within the experience of ambiguous loss, the current literature informs the general understanding of how this could be applied. For example, Golish and Powell (2017) used a dialectal perspective to "examine the grief processes and corresponding communicative responses of family members who experienced ambiguous loss of a premature birth" (p 328).

DMT has been used as an intervention in studies about children experiencing bereavement (Philpott, 2013), hospitalization (Tortora, 2019), and a cancer diagnosis (Cohen & Walco, 1999) with positive outcomes. While these topics share themes similar to ambiguous loss, they show the need for further research and interventions within the dance/movement therapy

field. Utilizing dance/movement therapy as an intervention in this method offers these participants a different avenue of expression.

In this method, I explored the experience of ambiguous loss with multiple participants who were medical patients at a pediatric hospital. I facilitated an individual dance/movement therapy session with participants on the transplant or oncology unit around the theme of ambiguous loss. By utilizing a dance/movement therapy method, these participants embodied an experience that is often difficult to find words to describe. The recognition of ambiguous loss within the medical and mental health field will provide patients with further, invaluable support throughout their hospitalization.

Literature Review

Ambiguous Loss

As previously mentioned, Pauline Boss coined the term ambiguous loss, and their research is foundational for this topic. Another way of describing ambiguous loss is as frozen grief, an incomplete loss, or an uncertain loss (Boss, 1999). The most pertinent examples, and research, of ambiguous loss, are subjects such as caregivers of dementia patients, refugees fleeing violence, and family members of missing persons (Nathanson & Rogers, 2020; Renner et al., 2021; Hollander, 2016).

Two proposed categories of ambiguous loss were addressed earlier, but they require further exploration and definition. The first type occurs when a support system views someone as "physically absent but psychologically present because it is unclear whether they are dead or alive" (Boss, 1999, p 8). In other words, this is a physical loss without proof of permanency. Examples include incarceration, divorce, persons missing following a natural disaster, and young adults leaving home, among other things (Boss, 2016).

The second type is the opposite experience; the person is physically present but psychologically absent. Examples include traumatic brain injury, chronic mental illness, and Alzheimer's disease. It is important to note that this type of loss can be experienced both within the family system and within the person themselves. "With both types of ambiguous loss, people must construct their own meaning of the situation within a paradox of absence and presence" (Boss, 2016, p 270).

While the experience of ambiguous loss is not inherently problematic, Boss (2004) identifies two factors that lead to harm or disruption. The first factor, boundary ambiguity, occurs when the family system becomes frozen. Boundary ambiguity is defined as "not knowing who is in or out of one's family system, and thus there is incongruence among individual perceptions about family membership and roles" (Boss, 2016, p 270). As a result, parenting roles become obscure, decisions are not made, and even "rituals and celebrations are canceled even though they are the glue of family life" (Boss, 2004, p 553).

The second factor is psychologically based and occurs "when there are feelings of hopelessness that lead to depression and passivity," which in turn can lead to feelings of guilt, anxiety, and even immobilization (Boss, 2004, p 554). The combination of these two factors, boundary ambiguity and feelings of hopelessness, begin to create a problematic experience of ambiguous loss. Closure is unattainable in both types of ambiguous loss, so this grief may continue to be felt across years, lifetimes, and possibly generations.

Several factors or tools have been identified to create positivity or certainty within the loss. Resilience and meaning-making are the overarching goals in supporting patients through ambiguous loss (Boss, 2010). Within this theoretical framework, resiliency means learning to comfortably live with a lack of closure and ambiguity (Brown & Coker, 2019).

To help clinicians effectively increase resilience within the experience of ambiguous loss, Boss (2016) proposed six guidelines: “finding meaning, adjusting mastery, reconstructing identity, normalizing ambivalence, revising attachment, and discovering new hope” (p 273). Boss (2010) also proposes moving into a both/and mindset, reconstructing one’s identity, re-evaluating one’s attachment to their image of relationships, and hope as the focus of treatment.

Meaning-Making

Meaning-making is perhaps the most emphasized goal in treatment within the theory of ambiguous loss. Meaning-making, as a goal, is found in literature not just around ambiguous loss specifically but also in topics such as bereavement, complicated grief, and chronic hospitalization. One cannot explore meaning-making without giving proper credit to Victor Frankl. In fact, Pauline Boss gives credit to Frankl:

> Who called for the search for meaning, a prelude to finding manageability and thus hope in even the most gruesome situation. To live with even the most horrific ambiguous loss, we help people find meaning in their experience, no matter how baffling it is. They may say that their loss will never have meaning, but that, too, is a meaning. Horror and irrationality exist. It is not their fault. When working with ambiguous loss, we shift from the goal of closure to the search for meaning because there is no other choice. The therapeutic work becomes necessarily more collaborative as we are no longer the only experts in the room. In the absence of facts and certainty about the family’s loss, we listen more and do less. We, too, learn to live with ambiguity and doubt—and hopefully find some meaning in their incurability (Boss & Carnes, 2012, p 464)

In Frankl’s memoir, *Man’s Search for Meaning* (2006), he writes about his harrowing time at a Nazi concentration camp during World War II. Through his traumatic experience, he

postulates that human suffering is inevitable, but finding meaning in the suffering makes life worth living. This very idea is at the core of logotherapy, his theory, which states that the primary motivation of human life is to find meaning. Understanding the development of meaning-making better informs the treatment goals of the ambiguous loss framework.

Ambiguous Loss with Hospitalized Children

According to the United States Health and Human Resources Department (2022), there are over 100,000 people currently on the national transplant waiting list. Almost 2,000 people on that list are children under the age of 18. Kidney, liver, heart, bone marrow, and lung are the most common transplants for children on the waiting list.

Children pre-transplant, post-transplant, and even those facing chronic gastrointestinal issues experience a plethora of emotions during their frequent hospital visits. For example, Walker et al. (2019) found that children awaiting a kidney transplant often felt anxiety, fear, and depression. At the time of transplant, worries about the operation, lack of emotional support, and guilt from taking attention away from siblings were identified themes. The post-transplant themes included concern about ongoing side effects, fear of transplant failure, and lack of emotional support during routine clinical care.

Anthony et al. (2014) examined the biopsychosocial impact on adolescents awaiting a pediatric heart transplant and its often grueling process. Several of the themes that emerged within this study are a “struggle” to survive, social isolation, lethargy, perceived physical weakness, and vulnerability. In addition, the themes from Walker et al. and Anthony et al. further implicate the possibility of ambiguous loss going unnamed or unrecognized within this population of chronically hospitalized children (p 651, 2019) (p 871, 2014).

Regarding bone marrow transplants, a procedure involving both the specialties of transplant and oncology, Breitwieser and Vaughn (2014) utilized a photovoice method to examine the emotional experience and coping skills of pediatric bone marrow transplant patients. Themes of physical and emotional pain, highly restrictive rules and regulations, feelings of isolation, and ambiguous discharge dates emerged from the data. Normalization, a sense of comfort in the hospital room, distractions, and social support were all identified as vital coping skills by the participants (p 290).

Boss and Couden (2002) propose utilizing the family-stress perspective when working with chronically ill patients around ambiguous loss. They identify five reasons why "the ambiguity surrounding an illness can make people feel helpless and thus more prone to depression, anxiety, and relationship conflicts" (p 1353). First, people are unable to make decisions and feel confused if there is obscurity around their diagnosis. Second, the familial reorganization of rules, rituals, and roles comes to a halt if there is no clear prognosis. In other words, the family structure freezes instead of adapting. Third, the grief goes unvalidated without a traditional loss, such as death, further freezing the support system from adapting. Fourth, the patient's worldview about what is fair and just is called into question in the fog of ambiguity. The fifth and last reason is that the longevity of chronic illness, and its ambiguous loss, takes a toll physically and psychologically, leaving those feeling fatigued (p 1359).

Ambiguous Loss and Research Studies

Kruetzer et al. (2016) found that patients recovering from a traumatic brain injury "experienced multiple losses, including altered self-image, increased self-doubt, and decreased confidence, the sum total of which created a state of identity ambiguity" (p 389). In addition, when examining the familial structure, loss of a sense of togetherness, individual identity, family

identity, future plans, goals, connectedness, and loss of emotional stability were all identified as common themes (p 394).

Golish and Powell (2017) used a dialectal perspective to "examine the grief processes and corresponding communicative responses of family members who experienced ambiguous loss of a premature birth" (p 328). Five primary communication strategies that helped alleviate stressors were identified as gathering information, educating family members, providing reassurance, creating a sense of teamwork with one's spouse, and highlighting the present moment.

A study conducted by Brown and Coker (2019) aimed to promote resiliency in African American teens experiencing ambiguous loss. The authors argue that children experience relational changes within the experience of ambiguous loss. Family supports, attachments, and communication can undergo significant changes while this loss occurs. They note that resiliency included living with ambiguity and a lack of closure in this context. Five qualities of resiliency were proposed: social competence, problem-solving skills, critical consciousness, autonomy, and a sense of purpose. Protective factors, both internal and external, such as a positive relationship with caring adults, were demonstrated as critical factors in resilience. In terms of resilience-focused interventions, Brown and Coker (2019) state:

> Resilience-focused interventions build personal strengths and emphasize adaptivity rather than focusing on deficits and problems beyond the control of the youth. For youth who experience ongoing adversity and trauma, therapeutic interventions that foster autonomy, competence, and connection while offering support for hopes and goals can foster resilience (p 290).

Dance/Movement Therapy

As previously mentioned, dance/movement therapy (DMT) is defined as "the psychotherapeutic use of movement to promote emotional, social, cognitive, and physical integration of the individual, for the purpose of improving health and well-being" (ADTA, 2022). Therefore, DMT can be applied across a wide range of populations and settings for various outcomes.

Several core beliefs inform the practice of dance/movement therapy. One of the most salient beliefs is that the mind, body, and spirit are interconnected. Movement is our first language, as one uses it to communicate before they can speak, which is a belief shared by all dance/movement therapists. All dance/movement therapists utilize movement as an assessment tool and a primary intervention (ADTA, 2022). These core beliefs lay the foundation of any dance/movement therapy practice, session, method, or intervention.

Pediatric Medical Dance/Movement Therapy

The expressive therapies, dance/movement therapy included, are not new to pediatric hospitals. Creative and expressive arts therapies departments in pediatric hospitals allow the patients a creative avenue for expressing any emotion that they may be experiencing during their hospitalization. The creative and expressive arts therapies department at any pediatric hospital provides invaluable support to the patients during their stay. DMT in a hospital setting is so critical that a unique form of dance/movement therapy has emerged called pediatric medical DMT:

> Pediatric medical DMT serves children and adolescents suffering from chronic, acute, or life-threatening medical conditions, including cancer, asthma, chronic pain, migraines, scoliosis, physical accidents, Tourette's syndrome, and other neurological disorders, heart disease, and prematurity and medical complications at birth. DMT is practiced in both

> inpatient and outpatient hospital settings, pediatric intensive care units (PICU), and private practice clinics. Adapting the definition of medical DMT to the pediatric population requires attending to additional aspects of the child's life including: developmental considerations; a greater focus on the nonverbal communication components of DMT for assessment and treatment; and considering the family and other systems in which the child is engaged, including school and peers (Tortora, 2019, p 3)

Goodill established the use of medical dance/movement therapy in the book, *An Introduction to Medical Dance/Movement Therapy: Healthcare in Motion* by defining the subspeciality, identifying clinical applications, emphasizing scientific discoveries, encouraging further research, and promoting future use of DMT in medical settings (p 15, 2005).

Dance/Movement Therapy and Ambiguous Loss

While there is no current literature on the direct application of dance/movement therapy as a method for understanding the experience of ambiguous loss with pediatric transplant patients, DMT has been used to explore ambiguous loss with other populations. For example, Mitchell (2016) illustrates how dance/movement therapy can support meaning-making. They utilized movements or dances with children in the foster care system around the topic of ambiguous loss.

Domingez (2018) utilized a transcendental phenomenological methodology to explore the guiding research question, "how is the lived experience of disenfranchised grief experienced by dance/movement therapists who work with clients experiencing disenfranchised grief?" (p 256). Five textural themes were identified; complex, pervasive, unrecognized, disconnecting, and overwhelming. In addition, four structural themes were identified; social/cultural factors, DMT approaches/interventions, kinesthetic empathy, and the therapeutic movement relationship.

One's identity, and role in the family system, can be called into question when chronic hospitalization is coupled with ambiguous loss. Erickson (2021) proposed an embodied identity development model based on a dance/movement therapy approach. "This model encourages counselors to view identity as an embodied, adaptable, cyclical and ongoing process rather than something cognitive, fixed, or achieved, and to engage clients in a continual process of self-discovery" (p 210). Movement and embodiment would allow one to explore their evolving identity; therefore, they would better be able to tolerate ambiguous roles or identities.

Depression, a symptom related to ambiguous loss, has been reported to decrease in adolescents when a dance/movement therapy intervention was utilized (Jeong et al., 2005). The results of this 12-week study with adolescent girls showed that DMT had "relaxation effects, stabilizes the sympathetic nervous system, and may be beneficial in improving the symptoms of mild depression" (p 1719).

Resilience as a primary goal in treatment is common in both dance/movement therapy and the theory of ambiguous loss. A mixed-method study was conducted to explore how dance/movement therapy could build resilience in people with chronic pain (Shim et al., 2019). Five fundamental mechanisms were identified in promoting resilience through dance/movement therapy: activating self-agency, connecting to self, connecting to others, reframing, and enhancing emotional wellbeing. By integrating these mechanisms into a DMT intervention, the participants reported increased self-efficacy, self-advocacy, and acceptance and demonstrated the fundamental characteristics of resilience (p 105).

Similarly, Serlin (2020) utilized DMT and a whole person approach to trauma and building resiliency. Four domains of resilience were identified: physical, psychological, social, and meaning and purpose. "A Whole Person perspective on resiliency brings together mind,

body, and spirit in an integrated healthcare model with a focus on meaning and purpose, wellness, strengths, creativity, and humor (p 179). DMT, and movement, are intertwined with this approach because "movement is a whole-person approach that helps clarify and release the stress, countertransference and burnout carried by both caregiver and the person in need of care" (p 180). The author implemented this approach and the results had outcomes that may help better inform clinicians on resilience.

Methods

Participants

Participants were three medical patients at a free-standing pediatric hospital who had received a consult for dance/movement therapy from a child life specialist. All participants were familiar with art therapy, music therapy, and child life specialists. Each participant had experienced chronic hospitalization as a result of their medical diagnosis. Each participant had received a transplant, though the type of transplant, diagnosis, and prognosis varied considerably between each. Each participant received individual dance/movement therapy sessions prior to and following this intervention.

Materials

Each participant was able to select their preferred music choice. Then, music was played through an Ipad provided by the hospital.

Procedure

The procedure of this method was designed to be broad and flexible. The setting, a pediatric hospital, proved to be an ever-changing dynamic. Unlike a traditional therapeutic setting, there was a constant flow of medical staff attending to each participant. It was not uncommon for medical staff to request the session be paused for medical interventions, such as

checking vitals, administering medication, or drawing blood. Along with staff, the tolerance for movement and perception of pain shifted throughout the session with each participant. Therefore, this procedure was created to be open, easily able to pause or stop, and applicable to a wide range of participants with various needs.

Each participant had previous experience with this me as the dance/movement therapist, though the degree varied greatly. Each session ranged from 30 to 75 minutes. The session began with a verbal check-in between us, in which topics brought forth by the participant such as pain, medical treatment, school, and tentative discharge dates were discussed. Once the verbal check-in had reached an organic pause, we transitioned to the movement warm-up. The movement warm-up began at the feet and worked up to the head. Slowly, the participant and I would stretch, contract, and bring attention to different parts of their bodies. Then, each participant verbally communicated any areas of pain or tension, and I would provide a modified movement if appropriate. There was a diverse range of movement among the participants. Each had specific, and different movement limitations or restrictions due to various medical reasons. Therefore, some parts of the body, such as the arms, were omitted from the movement warm-up.

Once the warm-up had concluded, I began a verbal discussion about ambiguous loss. I never explicitly used the term loss to keep the language appropriate for the age range. I would then ask, "what has changed since you have been in the hospital?". A written list, that was later thrown away, was made of the participant's responses to the question. While the list was being made, the participant created a movement or a gesture to represent each item. For example, the movement of writing with a pen could represent schooling or putting arms above the head, in a triangle shape, to represent home. Once the participant felt the list was complete, the gestures or movements were combined into a sequence. The participant and I would enact the sequence of

movements three to five times before coming to a close. By moving through the gestures, without stopping in between, the participants were able to fully embody the meaning of their movements.

As a source of closure for the movement portion of the session, I would ask, "what are you looking forward to?". This question was specifically asked to target areas of hope, meaning-making, and resilience within the participant experience. The participant would then go through the same process of making a list and creating gestures as before. For example, putting a hand to the mouth to represent food. This new sequence would be enacted three to five times as well. Once the participant felt they had completed their movement, there would be a transition to a verbal closure of the session. I would verbally inquire about how the participants felt, if they found moving to these questions was helpful, and if they felt different in their bodies. Before leaving the participant, the participant and I would make a plan for when the next session would be.

Record Keeping

Progress notes were written after each session. My site supervisor reviewed these notes, and submitted the notes to the hospital system. The progress notes described the duration, location, treatment goals, intervention goals, and the implemented dance/movement therapy interventions. In addition, the participant's response, affect, willingness to engage, and communication style were included in the progress note. The progress notes were required to be succinct and easily interpreted by medical professionals who do not have creative arts training. Due to this, critical DMT language, observations, and movement assessments were not documented through the progress note. Instead, the progress note served as a general summary of the session.

Due to the nature of the progress note, I kept a secure journal throughout the entirety of the process. The journal's purpose was to provide rich documentation that the progress notes limited. After each session, the journal was heavily utilized to track any thoughts, themes, and speculations. Lists, essential words, movements qualities, and observations were also documented after each session. I utilized the journal to explore any questions and biases that emerged throughout the process. The journal waas coded and kept in a secure, locked place throughout the entirety of the inquiry.

Along with the progress notes and journal, I conducted a personal, improvisational, movement response after each session. This exploration aimed to digest and embody the experience of this research. The movement response was done in various quiet spaces either in the hospital or in my home for approximately five to ten minutes. Within the movement response, the themes, movement qualities, and my overall reaction to the intervention of the session were explored. The movement response provided a richer understanding of the participant's experience and the overall experience of the intervention.

Results

Intervention #1

This participant was a post-transplant adolescent male with a developmental delay and a complex medical history experiencing long-term hospitalization. The session took place in the participant's hospital room, lasting approximately 75 minutes, with the participant sitting down for the entire duration. A support person was present throughout. This support person was present for all previous sessions; therefore, their presence was normalized in the therapeutic space. Throughout the session, there were two interruptions. The first occurred when

housekeeping entered to complete their daily clean. The second occurred when the unit's Child Life Specialist briefly checked in with the participant.

The participants easily engaged in the verbal check-in. The participant verbalized frustrations with their medical status and ongoing social situations. Once these frustrations were verbalized, the participant transitioned to the movement warm-up. The participant's movements were small and stiff. During the warm-up, the participant discussed a medical procedure they had the day prior. The participant made a plan to modify movements that would be uncomfortable due to this.

The participant identified eight categories as things that have changed due to their hospitalization: school, friends, church, family, body, food, home, and sleep. The participant was quickly able to create coinciding gestures to compliment the list. They had a knowledge of sign language, which heavily influenced their gestures. The lower body was not used in any of the movements created. The arms and hands were the primary limbs used for movement. The participants did utilize their chest and head for two of the eight categories. They struggled to remember the order when asked to put the sequence together and move through it several times. However, once told the next word, they quickly recalled the gesture associated with it. The participant kept a slow, steady pace as they moved from gesture to gesture.

The participant was able to identify five things they were looking forward to: birthday, cake, family, nice dinner, group home. Interestingly, each of these relates to things they stated had changed. The participant verbally explored and explained the list more than the previous one. They went into great detail about the scenarios they were looking forward to. When talking, they were smiling, making eye contact, and laughing. Similar to the last portion of the session, they could easily assign gestures to the list and utilized their knowledge of sign language. Due to

the list being shorter than the previous, they required fewer reminders about the orders or content of the movement sequence. The movements were larger and more expansive than the previous list. The sequence was enacted with a quick and light pace.

During the verbal closing of the session, the participant reported positive emotions linked to the intervention. The participant stated that both movement sequences had felt good and did not have significantly different feelings about one. The participant even reported that they had begun journaling recently and felt that talking about the things that had changed was beneficial to write about. In addition, the participants' body language appeared to be more open, and they were observed making more eye contact compared to the beginning. While I was exiting the room, the participant waved goodbye.

Intervention #2

This participant was an adolescent female who was awaiting a transplant. This participant had a complex and traumatic medical history that required frequent, chronic hospitalizations. The session lasted approximately 45 minutes and was conducted at their bedside. Three interruptions occurred during this session; the first was a medical staff who needed to collect vitals. The second was a phone call the participant got from the pharmacy. The third was a medical staff who needed to administer medication. During the verbal check-in, the participant reported pain in their abdomen, gave medical updates, and provided general social updates.

When asked about things that had changed, the participant initially struggled to create a list. They reported feeling that they had spent such a significant portion of their life in the hospital that they knew nothing different. Eventually, they were able to make a list of things that had changed in the past few months rather than since their hospital admission. They were able to create a list of eight things: classes, social media, medication, body, medical team, food, anxiety,

and depression. They gave a detailed explanation for each of these categories. The participant could easily identify how these things had changed and what emotions they linked to it.

As the participant was getting ready to create gestures or movements for the list, their level of pain increased significantly. Due to their pain, the participant requested that the session be paused. A plan was made between the participants and I to return the following week to complete the intervention. However, the participant was discharged during the weekend, so the intervention was not fully completed.

Intervention #3

This participant was a child, female, who was recently placed on post-transplant status and was awaiting a second transplant. This participant has a relatively new diagnosis within the past year, resulting in chronic hospitalizations for medical treatment. This session took place in the hospital's Creative and Expressive Arts Therapy group space and lasted approximately 45 minutes. This space contains various expressive arts therapy materials and resources, including a video projector which the participant gravitated towards. Immediately before this participant came to this space, they received news that they would require a second transplant. Therefore, emotions appeared to be heightened throughout the session.

During the verbal check-in process of the session, the participant appeared quiet. They gave limited verbal feedback, avoided eye contact, and often shrugged their shoulders when asked a question. It appeared that this was an emotional response to the medical update earlier. In addition, the participant reported feeling hot and itchy, which had been a common symptom of their transplant. Overall, during this check-in, their body language was small and inward.

The participant was able to identify three things that had changed since their hospitalization: body, family, and school. The participant was limited in their ability to verbalize

how these had changed. Surprisingly, the participant easily created the gestures created for these categories. The movement was light, flowed together, and primarily utilized the arms. When moving through the sequence, the participant maintained eye contact.

When asked about what they were looking forward to, the participant could only identify one thing: going home. The participant verbally processed their frustrations about their hospitalization and prognosis. They expressed feeling like they were being kept at the hospital. However, the participant could identify the things, such as pets, that they were looking forward to seeing at home. During this conversation, the participant became emotional and requested to return to the room where their mother was. They stated they were happy to be able to come to the creative arts space, but now they were tired.

Discussion

The current method examined the effects of ambiguous loss with medical transplant patients in a pediatric hospital by utilizing a dance/movement therapy intervention. This method was developed based on ambiguous loss theory with a dance/movement therapy approach. The literature that was explored identified central themes of ambiguous loss, such as resilience. These themes were connected to the practice of dance/movement therapy, such as embodiment. With this connection, the intervention was developed and implemented with three participants. One child and two adolescents were participants in this intervention, and each was treated as a separate, individual intervention. All three of the participants had or was awaiting a form of transplant.

A verbal check-in began the session with each participant. This provided opportunities to discuss pain, medical changes, and personal updates. Then each participant created a list of things that had changed due to their hospitalization. The goal of this list was to explore potential

areas of ambiguous loss. Next, two of the three participants were able to create movements or gestures related to the list. Once the movement sequence had been explored, two of the three participants made another list of things they were looking forward to. The goal of the second list was to explore areas of hope, meaning-making, and resilience. They then repeated the same movement process. As a closure to the session, only one participant verbally processed the experience. This intervention produced rich results that deepened my personal understanding of ambiguous loss with chronically hospitalized children.

Movement Opening Up a Conversation

While not the primary motivation for the development of this method, this intervention created the space for therapeutic conversations around loss and change. Previously, Golish and Powell (2017) utilized a dialectical perspective when exploring the perspective of people who had experienced premature birth. The five primary communication strategies that helped alleviate stressors were gathering information, educating family members, providing reassurance, creating a sense of teamwork with one's spouse, and highlighting the present moment.

Several verbal communication strategies identified by Golish and Powell (2017) were explored non-verbally throughout this study, such as highlighting the present moment and gathering information. Similarly, Brown and Coker (2019) highlighted communication as something that undergoes significant, often negative, changes during a time of ambiguous loss. By relating the examined literature to the qualitative theme of this intervention, it may be inferred that dance/movement therapy allows one to feel supported and validated non-verbally. Through this, one may feel more comfortable verbally processing the experience of ambiguous loss.

The Human Body

All three participants identified their bodies as something that had changed due to their hospitalization. This theme relates to Boss's (1999) category of ambiguous loss when someone is psychologically present but physically absent. Rather than a family member or caregiver witnessing a loved one's body evolve, the participants themselves watch and feel their bodies going through drastic changes each day. This invention highlighted the participant's experience of this, and opened up a verbal and non-verbal dialogue about the bodily changes they were experiencing. Dance/movement therapy is uniquely equipt at helping one become reacquainted with their body. This intervention may allow future inquiries to explore the connection between medical changes in the body and a dance/movement therapy intervention as a coping method.

Family

Two of the three participants identified their family as something that had changed due to their hospitalization. A significant portion of the literature, including but not limited to Boss (2016), Walklet et al. (2019), Boss and Couden (2002), and Kreutzer et al. (2016), identified the family structure as a crucial element in creating positivity within ambiguous loss. The significance of the family structure was further emphasized by two participants identifying it as something that had changed. The nature of this change, whether positive or negative, was not explicitly discussed during the session. However, the theme of the family or support system changing and its specifics may be explored further in future studies.

School

Each of the three participants identified school as something that had changed due to their hospitalization. Interestingly, this was not touched upon in any literature that was explored. This pediatric hospital offers an online school program to hospitalized patients for long periods. At the time of this project, one of the three participants was enrolled in this program. One participant

elaborated that they had fallen behind on schoolwork during their hospitalization, while another identified socialization as a part of the school they missed. One participant did not verbally elaborate on their school experience. Two of the three participants created similar gestures for school. They both utilized their hand and made writing motions in the air to imitate writing a paper.

Home

Home was explicitly identified as something that had changed by two of the three participants. The third participant inexplicitly identified home due to their statements about being home for short periods of time. Boss and Couden (2002) suggested that the reorganization of familial rules, roles, and rituals can halt while a child is hospitalized. I am interested if they had experienced a change in the rules, roles, and rituals at home. The freezing or changing of these family structures could lead to further stress on the patient during times of ambiguity (Boss & Couden, 2002).

Meaning-Making and Resilience

The purpose of the second prompt with this intervention, identifying what the participants were looking forward to, was to emphasize mean-making and hope. Meaning-making and resilience were identified as critical elements of coping with ambiguity in times of loss. Boss (2016) proposed six guidelines: "finding meaning, adjusting mastery, reconstructing identity, normalizing ambivalence, revising attachment, and discovering new hope" (p 273).

Two of the three participants were able to identify things that they were looking forward to or hope. One participant was unable to complete the intervention due to pain management. The first participant identified their birthday, cake, family, a nice dinner, and moving into a new home as things they were looking forward to. The second participant identified going home as a

source of hope. Boss (2016) identified discovering hope as a critical element in treating ambiguous loss. Shifting the treatment focus from closure to finding new meaning is also a critical theme (Boss & Carnes, 2012).

Interestingly, remission, recovery, or health was not identified as anything these participants were looking forward to. One may assume that these participants have already shifted from finding closure, or medical recovery, to a new meaning, such as going home. By the participants not identifying health, it infers that the participants already have a tolerance for ambiguous health and an admirable level of resilience and meaning-making.

Movement Response Videos

Three movement response videos were made after each intervention and lasted approximately five to ten minutes in length. After the first intervention, I observed feelings of longing and excitement within myself. My hands, arms, and upper body were primarily utilized in my movement. I found myself creating similar gestures that the participant used. When reflecting upon the first movement sequence about what had changed, I found my movements to be slow, elongated, and heavy. On the other hand, my movements were quick, small, and anticipatory when reflecting upon what the participant had stated they were looking forward to. I felt a sense of relief within my body after concluding this movement response.

During my movement response to the second video, feelings of hesitation, uncertainty, and lack of resolve or closure emerged. My movement reflected these feelings by never quite finishing. For example, my arm would never fully reach out in length. My body language was closed and small. I found myself reaching into my kinesphere rather than creating movements that reached out. Generally, I found myself moving slowly, never sure what movement would be next. However, there were moments of quickness that felt frantic within my body. This

participant was still awaiting a transplant, and I found myself embodying the emotions the participant had expressed about this wait. After bringing the movement to a close, I felt weighted, stagnant, and tight.

The final movement response videos allowed feelings of hope, anticipation, and exhaustion to emerge. I found myself moving quickly, free, and light. My movements were long, outstretched, and circular. While there was an overall quickness to my movement, there were several moments of stillness. To me, the stillness represented the time in between transplants. My head, arms, and legs were primarily used in this movement response. Once this movement response had concluded, I felt resilient, tired, and hopeful all at once.

Recommendations and Limitations

There are several limitations of this project that should be addressed. The second participant was unable to complete the intervention. Therefore, their data was left incomplete. Second, the therapeutic space, or container, had to be adapted for interruptions. Third, due to the ongoing COVID-19 pandemic, for the health and safety of all, masks were worn at all times. The masks may have blocked certain facial expressions or emotions from being communicated. Finally, the duration of the intervention is also a limitation. Unfortunately, due to the nature of the hospital setting, many patients are discharged without notice, so a multiple session method was not plausible. It would be recommended that a future study explore ambiguous loss through multiple dance/movement therapy sessions.

Regarding recommendations, video recordings of future studies may provide more fruitful data. In addition, a group session, rather than an individual one, may allow participants to discuss their experience of ambiguous loss with one another, leading to a richer understanding of the overall experience. On a similar note, future research would be recommended to focus on the

parent's experience of caring for a chronically hospitalized child. Much of the current literature supports this viewpoint. Finally, a multi-model approach within expressive arts therapies is recommended to allow for different avenues of expression if movement is not appropriate due to pain or tension in the body.

Conclusion

This method demonstrates how the experience of ambiguous loss can be explored through dance/movement therapy with hospitalized children. The results of this intervention indicate that the body, family structures, and school, among other things, experience significant changes during a time of medical ambiguity. In contrast, the hope of going home provides a source of resilience and meaning-making to overcome the experience of ambiguous loss. Furthermore, dance/movement therapy provided a non-verbal avenue for the participants to explore, embody, and express their ongoing losses. In turn, this non-verbal exploration allowed them to verbalize their emotions, be validated in their experiences, and strengthen the therapeutic relationship. Hopefully, this method implores researchers in the future to further examine the experience of ambiguous loss and all of its complexities.

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Author Acknowledgments

I would like to express my deepest gratitude to Kory Antonacci for her invaluable guidance and support. Thank you to Jessica Young and Meg Chang for your teachings and supervision throughout this process. To my family and friends, you all were the pillars of my support system throughout this entire process, and I will be forever grateful.

THESIS APPROVAL FORM

Lesley University

Graduate School of Arts & Social Sciences

Expressive Therapies Division

Master of Arts in Clinical Mental Health Counseling: Dance/Movement Therapy, MA

Student's Name: Peyton Edington

Type of Project: Thesis

Title: Moving Through Loss: The Experience of Ambiguous Loss with Hospitalized Children, Development of a Method

Date of Graduation: May 21, 2022

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

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