

The Use of Songwriting to Explore Anxiety Related to Food Allergies: A Heuristic Self-
Inquiry

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A Thesis
in
The Department
of
Creative Arts Therapies

Presented in Partial Fulfillment of the Requirements
for the Degree of Master of Arts (Creative Arts Therapies, Music Therapy Research
Thesis Option)
Concordia University
Montreal, Quebec, Canada

April 2024

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ABSTRACT

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Adriana Caruana

Life-threatening food allergies affect individuals on various levels, from their quality of life and mental health to the threat they impose on their safety. There is a gap in existing research that examines how music therapy might help individuals address food allergy related anxiety. As someone who has lived with a life-threatening peanut allergy my entire life, I have experienced the many complications and challenges that one faces when it comes to navigating their way through the world. The purpose of this self-heuristic inquiry was to use songwriting as a means to explore my food allergy-related anxiety. I generated data by composing a total of four original songs, each of which explored a specific topic using a writing prompt, regarding my experience of living with a food allergy. Data analysis produced three main categories that provide insight into broad perspectives on my experience, or what I call, the big picture, experiences of the additional labour that living with an allergy requires, and the varied emotions that I experience in diverse contexts. I conclude with a creative synthesis; an original song that synthesizes insights derived from the research process. Finally, this paper concludes with implications for my music therapy practice which include insights about how I can utilize the tools that I have gained throughout this process to support individuals through music therapy who live with life-threatening food allergies.

ACKNOWLEDGEMENTS

To my incredible husband. Michael, you are my greatest blessing. From the moment I expressed my desire to complete this Master's degree, you have been nothing but supportive. Thank you for being my rock and for always encouraging me to pursue my dreams.

To my parents who have been alongside me in my academic journey since the first day I ever walked into a classroom. Thank you for pouring into me and cheering me on every step of the way.

To my big brothers. The countless hours of high school math tutoring taught me to never give up and to keep working harder. Years later, here I am. I did not give up. Thank you.

My sisters in laws who are my sisters. Thank you for bringing into this world the most precious gifts; my three little nieces. You have brought Zia so much love and life throughout this writing process. Thank you for making me smile through it all.

To my grandparents, Nonna and Nonno. The greatest gift I could have ever received was being able to grow up knowing the unconditional love of grandparents. Vi voglio tanto bene.

To all of my in- laws, my new family. Thank you for accepting me and making me feel like one of your own.

To my best friends, thank you for growing with me and being by my side through all of life's phases.

To my supervisor, Dr. Cynthia Bruce. Thank you for your feedback, support and wisdom, in helping me grow and understand more about myself throughout this process.

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Chapter 1. Introduction

Personal Relationship to The Topic

The topic of food allergies and anxiety holds great importance for me since I have been living with a life-threatening peanut allergy since the age of approximately 19 months. Living with an anaphylactic allergy has affected my life in several ways and has, at times, caused me anxiety and stress. It has impacted the spaces I occupy, my state of awareness, but mostly, it has impacted and threatened my safety. Although I do not experience anxiety related to my food allergies on a daily, weekly, or even monthly basis, it is an area of concern in particular isolated instances, for example when traveling abroad or when attending social gatherings. Anxiety, then, is never far; it hides under the surface of numerous, seemingly mundane, experiences.

Significance of The Inquiry

Food allergies affect a small, but significant portion of the population. It is estimated, in fact, that 6% of young children and 3-4% of young adults in Canada are affected by food allergies (Government of Canada, 2021). According to Food Allergy Canada (2024), food allergies are a public health issue since there is currently no cure for those who live with this diagnosis. There are approximately 3 million Canadians who self-report having one food allergy, 600,000 Canadian children with food allergies, and 2 in 100 Canadian children diagnosed with a peanut allergy (Food Allergy Canada, 2024). Furthermore, Xu et al. (2014) found that between 1986 and 2011, a total of 92 deaths in Ontario were associated with anaphylaxis.

According to the literature, food allergic individuals often live with anxiety related to their food allergies. Manassis (2012) states that food allergy anxiety can become so debilitating for children who deal with anaphylaxis, that it can prevent them from engaging in certain social activities within or outside the home. There currently remains a gap in our understanding of how to meaningfully support individuals experiencing anxiety associated with having a life-threatening allergy.

The number of individuals affected by allergies extends beyond the individual who is diagnosed. Literature also points to the anxiety experienced by family members of those who live with life-threatening allergies, particularly parents of food allergic individuals (Birdi et al., 2016). There is, accordingly, a need for the food allergy community to have access to supportive strategies that will help them cope with the associated stressors. Current literature positions

music therapy as a helpful resource for individuals who experience anxiety for diverse reasons (Bruscia, 2014). There is, however, little to no research that specifically examines the use of music therapy to support individuals who live with life-threatening food allergies. As a new music therapist who lives with the daily realities of a life-threatening diagnosis, I became interested in exploring my own experiences in order to consider how they might be mobilized to support others who live with this diagnosis in my music therapy practice. I, therefore, chose a heuristic self-inquiry to explore and uncover how songwriting could facilitate an exploration of my lived experiences of having a life-threatening peanut allergy.

Statement of Purpose

The purpose of this study was to explore the insights that might emerge for a new music therapist engaging in a reflexive songwriting process about her experiences of anxiety associated with having a life-threatening peanut allergy.

Research Questions

The primary research question was: What insights might emerge when I, a new music therapist, engage in reflexive songwriting to explore my experiences of living with a life-threatening food allergy? The subsidiary questions were: 1) what insights, if any, will be related to experiences of anxiety? 2) what insights, if any, will be related to interpersonal relationships and support? And 3) how might these insights contribute to my music therapy practice?

Assumptions

Prior to beginning this inquiry, my main assumption was that music (specifically songwriting) would indeed be a helpful tool to allow me to explore and express my thoughts and feelings about my food allergy. Another main assumption was that this process would allow me to explore potential implications regarding my work as a music therapist.

Key Terms

Anxiety (generalized anxiety disorder), “is associated with substantial reductions in quality of life and deteriorated functionality” (Gutiérrez & Camarena, 2015, p. 19). *Food allergy* “occurs when the body’s immune system sees a certain food as harmful and reacts by triggering an allergic reaction.” (Food Allergy Canada, 2024). *Anaphylaxis* is “a serious allergic reaction that is rapid in onset and may cause death.” (Food Allergy Canada, 2024). According to Wheeler (2015), “*music therapy* helps people to develop skills, adapt behavior, and overcome obstacles in their lives. Music therapists use different kinds of musical experiences, including improvising,

performing, composing, and listening, along with talking about people’s experiences, to meet clients’ needs by utilizing the unique relationship between the client, the music, and the therapist” (p. 5). It also “requires the involvement of a music therapist so that the music can be used for interactive communication” (Nguyen et al., 2010, p. 147). *Passive music therapy* “entails listening to music for a particular purpose, recorded or live, without the involvement of a music therapist” (Nguyen et al., 2010, p. 147), also known as music medicine. *A new music therapist* is someone working professionally for less than two years. *Reflexive Music Therapy*: Bruscia (2014) explains that in *reflexive processes*, “the therapist makes continuous efforts to bring into awareness, evaluate, and, when necessary, modify his work with a client –before, during, and after each session, as well as at various stages of the therapy process” (p. 36). *Reflexivity* is “the ongoing and continual focus of one’s consciousness on all aspects of one’s work with clients, along with modification of the work as necessary” (Bruscia, 2015, p. 8-9). *Songwriting* “is a creative process, and like improvising, it involves a host of decisions. The songwriter selects a medium (e.g., voice, instrument), selects a sound vocabulary, explores the options of the medium and vocabulary, creates certain entities and sequences thereof, evaluates the options chosen, and then starts again to explore the myriad options for continuation” (Bruscia, 2023, p. 154).

Summary of Chapters

The following heuristic inquiry will be organised amongst five chapters. The first chapter discusses the significance of the study, articulates the purpose of the study, and establishes the research questions. It also outlines the key assumptions and definitions of key terms. Chapter 2 is comprised of a literature review which is divided into two main sections; The experiences of those who live with food allergies and the use of music therapy for individuals with health related anxiety. Chapter 3 explicates the methodology, more specifically the study design, the materials used, the delimitation and ethical considerations of this study, as well as the process of collecting and analyzing the data. Chapter 4 articulates the findings of this research. Finally, Chapter 5 addresses the limitations of the study, personal and professional implications, recommendations for future research, as well as my closing thoughts.

Chapter 2. Literature Review

This chapter aims to explicate existing literature in two main areas. First, it will examine the literature pertaining to the experiences of those who live with food allergies and the anxiety they experience as a result. These domains include the additional labour they must undertake in order to stay safe, the fear caused by potential contact with their allergen, and the related responses from others in their surroundings. Then, literature will be examined related to how music and music therapy are used to support anxiety experienced in specific healthcare contexts that closely resemble experiences of individuals with food allergies. This includes areas such as support for anxiety, depression, fear of the unknown, and procedural anxiety and pain.

Lived Experiences of Food Allergies

Allergy-Related Daily Necessities

Literature suggests that individuals with food allergies experience a wide variety of quality of life impacts that are connected to their allergy related health status. These daily living impacts can affect their health-related quality of life (HRQL) which Bacal (2013) defines as “an individual’s or group’s perception of the effect of an illness and its treatment on their quality of life and activities of daily living” (p. 142). There are often burdensome tasks associated with living with a food allergy. Even though these allergy-related daily tasks can become quite laborious, they are necessary to ensure safety for the food allergic individual.

Le et al.’s (2008) study demonstrates how allergies can impact day to day life, especially when leaving the comfort of one’s home and, therefore, undertaking the required tasks to ensure safety. The authors examined the differences in clinical severity among participants with three differing allergies: tree nut allergies, peanut allergies, and fruit allergies. They also studied how the clinical severity was reflected by impact on daily life and prescription emergency medication. Participants were asked to complete a questionnaire about their food allergy symptoms – the food reactions were organized according to affected organ systems. Participants were also asked about their emergency medication; those who were prescribed an epinephrine auto-injector were also asked about its use and the impact on their daily life. Using a five-point scale, the authors studied whether food allergies affected life inside and outside the home. Skin prick and Specific Immunoglobulin E tests were performed on selected patients. The results indicated that 55% of participants in the peanut/tree nut group and 60% of participants in the fruit allergy group, stated that their food allergies influenced their daily life at home, and 72% and 62% explained that it

impacted their life outside in a more significant manner. Notably, 65% of the participants reported the need to carry an epinephrine auto-injector. This highlights a reality for children with peanut allergies who must, according to literature, be consistently vigilant and carry as a precaution, an epinephrine injector as a life saving resource in case they come into contact with peanuts (Avery et al., 2003).

Literature points to differential quality of life impacts between women and men with food allergies. Beyer et al. (2016) had two main goals for their study; to validate the German “Food Allergy Quality of Life Questionnaire- Adult Form” (FAQLQ-AF) and to determine the health-related quality of life (HRQL) in adults with birch pollen-associated food allergies. The participants were comprised of men and women with a median age of 43 years. Participants were asked to answer questions on their food allergy triggers and symptoms in addition to answering questions from the FAQLQ-AF which was comprised of 29 questions on a 7-point scale. The questions were assigned to four subscales: a) Allergen Avoidance and Dietary Restrictions, b) Emotional Impact, c) Risk of Accidental Exposure, and d) Food Allergy-Related Health. The results from the FAQLQ-AF indicated differences between men and women. When it came to everyday life, women felt more impaired because of their allergies, especially when it came to social activities. The results also showed differences in HRQL between the older and younger participants. Women in the older group were more fearful of an allergic reaction, felt sadder about their food allergy, were more concerned regarding eating outside the home and felt like a burden when others hosted them. Additionally, women with multiple food allergies had lower HRQL in two of the subscales of the questionnaire. The authors speculate that this may be due to the lack of involvement in social activities as they might not frequent restaurants or attend family gatherings. Therefore, in an effort to avoid contact with their allergens, women’s HRQL and everyday life was noted to be impacted.

Food allergic individuals often take specific actions to maintain their safety when food is present. Peniamina et al. (2014), explored the unmet needs of food allergies in a participant group that included adults whose mean age was 43.6 years. Participants were diagnosed with a range of food allergies. Prior to attending the focus group, participants completed an online survey and their responses were used as part of an introductory exercise that asked them to rate each of a number of statements based on its level of allergy impact. After this whole group introductory exercise, participants were divided into four focus groups; and those focus group

interviews lasted between 90-150 minutes. Focus groups fostered discussions about their food allergies and how they impact their everyday lives. Results were categorized into three main categories: a) issues related to living with a food allergy, b) external influences, and c) internal influences. Findings highlighted the difficulty that all participants experience when eating out at restaurants, and noted how a seemingly simple task can easily become quite stressful for food-allergic individuals. Strategies to navigate this stressful event included calling restaurants in advance, researching the menu online to check for safe options, or ordering the same dish each time. When attending social events with shared meals, strategies included bringing several dishes in order to be able to eat, or having their meal served first in order to avoid cross-contamination. Participants similarly noted the significant impact of their food allergies on their social well-being, stating “anything to do with food you don’t join as much. That’s just life. It’s just too stressful” (Peniamina et al., 2014, p. 939).

Finally, participants highlighted the need to always be organized which included having to plan meals in advance and always ensuring they carried a safe snack with them. Participants also spoke about the need to be assertive when explaining their allergies to others and the importance of emphasizing the severity of their diagnosis. The authors categorized personal growth and adaptation as internal influences, which affected how food allergic individuals cope with their allergy and how they perceive its impact on their quality of life.

Allergy-Related Fears

Food allergic individuals often fear the consequences of coming into potential contact with their allergens. This fear can make them hypervigilant and lead them to avoid foods and social situations. This ever-present concern can produce anxiety and related mental health issues.

Avery et al. (2003) examined quality of life by comparing scores between 20 children with peanut allergies (PA) and 20 children with insulin-dependent diabetes mellitus (IDDM). Participants completed disease-specific quality of life questionnaires. They were also given a disposable camera and a notebook to record how their diagnosis impacted their quality of life during a 24-hour period. Participants with IDDM constituted the control group because they often experience similar challenges to those with food allergies in terms of food choices, social restrictions, carrying medication, and the chronic nature of the diagnosis. Findings suggest that children with PA experienced more impaired quality of life than children with IDDM. Impaired quality of life was demonstrated by statements that cited close proximity to peanuts as something

that made them fear for their lives. Children with PA also reported increased fears of experiencing adverse reactions to peanuts and greater anxiety about eating, especially when eating away from home. Notably, two PA participants said they were afraid of dying when they knew they were near peanuts. The authors specifically noted that poorer quality of life in children with PA is related to anxiety, and also the knowledge that exposure to their allergen can produce fatal consequences- anxiety that can lead to mental health issues in food allergic children.

Bacal (2013) similarly highlights the burdensome role of hypervigilance in the lives of food allergic children and their families. This added burden manifests in a need to read food ingredients lists on labels and to plan and bring food to social events. This hypervigilance in avoiding food allergens, can negatively affect children's quality of life because they become fearful of accidental exposure (Bacal, 2013). Bacal (2013) also explains that children may fear that any accidental exposure will lead to their death.

Anxiety, similar to overall quality of life, is a common struggle among this group. According to Feng & Kim (2019), children appear to experience significant levels of distress related to living with a food allergy. Weiss & Marsac (2016) examined coping and posttraumatic stress symptoms (PTSSs) in children aged 7-13 with at least one confirmed food allergy. Participants completed a self-report questionnaire, a Child PTSD Symptom Scale and a determination of subsyndromal PTSD. The results indicated that all of the participants used three types of coping to manage their food allergies; cognitive restructuring, social support, and avoidance. Notably, two out of 25 children met the criteria for post-traumatic stress disorder (PTSD) and 9 subjects met the criteria for subsyndromal PTSD. Higher levels of posttraumatic stress symptoms (PTSSs) were found in children who had experienced anaphylactic reactions compared to those who had not. While avoidance might be necessary to prevent additional exposure to an allergen, avoidant coping can also pose a risk to psychological health (Weiss & Marsac, 2016).

Manassis (2012) reviewed the medical literature on anxiety and anaphylaxis in children and youth and examined the findings on anxiety management in food allergic children and their parents. The author found that the literature points to the possibility for anxiety to become debilitating and to impose unnecessary restrictions on the anaphylactic child's life. This prevents the child from engaging in activities at home, school, or in social interactions. Manassis' (2012)

findings point to four overall aspects of anxiety; physiological aspects of anxiety, cognitive aspects of anxiety, behavioral aspects of anxiety, and parental aspects of anxiety.

The author notes, importantly, that some physiological manifestations of anxiety can be mistaken for allergic reactions. Children with food allergies can, for example, become fearful that they have come into contact with their allergen when experiencing anxiety because hyperventilation that is associated with anxiety can result in tingling of the lips and extremities—symptoms that mirror reactions that result from exposure to an allergen. It is suggested that children could benefit from relaxation techniques such as slow, deep breathing, progressive muscle relaxation, and box breathing.

Cognitive aspects of anxiety, according to Manassis (2012) acknowledges that children with food allergies have different worries than their non-allergic counterparts. They have worries about life-threatening, high risk events. In order to help reduce anxiety, educating the child (and their parents) on how to manage the risk and the degree of the risk in certain circumstances, can be beneficial. This way, the child can be aware and participate in the active planning of risk management.

Manassis (2012) explains that behavioral manifestations of anxiety consist of “unnecessary avoidance of certain situations or excessive clinginess with parents” (Manassis, 2012, p. 5). Some food allergic children will restrict food intake which affects their weight and nutrition. Manassis (2012) importantly argues that in order for anaphylactic children to function well in society, their anxiety must not be excessive. Therefore, the physical, cognitive and behavioral manifestations of anxiety must be addressed.

Separation anxiety is often, and perhaps not surprisingly, found in individuals with food allergies as they begin to gain independence from their parents. Bacal (2013) explains that separation anxiety is a necessary developmental milestone which usually ends when a child reaches 2 years of age. It can, it is important to note, return during later stressful moments. This anxiety can have an impact on a child’s schooling and their social functioning because they may find it challenging to be away from their parents. Bacal (2013) argues that for a child with food allergies, “returned separation anxiety and stress is justifiably warranted as the child overhears his or her parent giving instructions on how to administer an epinephrine auto-injector in the event of an emergency” (p. 143).

King et al. (2009) observed such separation anxiety in a study that examined the impact of peanut allergies on quality of life, stress, and anxiety in peanut allergic individuals and their families. Families who had a child with a peanut allergy along with the peanut allergic child, completed scales for anxiety (SCAS or STAI), perceived stress scale (PSS) and quality of life (Peds-QL™ or WHOQOL-BREF). Children with peanut allergies completed a peanut specific QoL questionnaire while parents and siblings completed quality of life proxy questionnaires for the child with the peanut allergy. The authors reported that children with peanut allergies had higher rates of separation anxiety compared to their siblings. This might be due to their fear of having to navigate and manage their allergies on their own without the help of their family.

LeBovidge et al. (2009) also noted experiences of separation anxiety in food allergic children. Mothers of children with food allergies completed questionnaires regarding their child's medical history, child anxiety, depressive symptoms, and maternal anxiety. Their children completed self-report measures of anxiety, depressive symptoms, social stress and attitudes toward food allergies. The children reported significantly higher anxious coping and separation anxiety symptoms compared to the normative scores. The authors stated that this indicates that children may experience "increased vigilance and checking behaviors or fears about going places without parents present" (p. 1286). Therefore, as children grow and learn to become more independent, there is fear associated with having to advocate and fend for themselves without the support and supervision of their parents.

Separation anxiety was also observed by Shanahan et al. (2014) who sought to determine whether adolescents with food allergies were at increased risk for psychopathology. Their longitudinal study followed three cohorts of children aged 9, 11 and 13 years old from eleven counties in North Carolina. Participants were assessed each year until the age of 16 and were interviewed separately from their parents. Longitudinally, the authors found that adolescents with food allergies had increased symptoms of generalized anxiety disorder and depression. They did not find that those with food allergies were associated with meeting diagnostic criteria for a psychiatric disorder. They did however find that cross-sectionally, participants had elevated symptoms of separation anxiety. Notably, while allergen avoidance is the primary successful allergy management strategy, adolescent participants were at increased risk for eating disorders. The authors explain that "given the changes in lifestyle and food intake necessary in the context

of food allergy, it is likely that, at a minimum, eating habits and behaviors, and feelings and cognitions about food and one's body will be altered" (Shanahan et al., 2014, p. 472).

The literature, unsurprisingly, documents experiences of depression, anxiety, and even bullying among adolescents with food allergies. Ferro et al. (2016) explored emotional and behavioral problems in an epidemiological sample of young people with food allergies. Participants included children who received services from a public prenatal care hospital, and their mothers, who had completed their 14-year follow-up. Data was collected by measuring self and maternal reported symptoms of depression, anxiety, attention deficit hyperactivity, oppositional defiant disorder, and conduct disorder. Maternal reports (not self-reports) "suggested that adolescents with food allergy were up to four times more likely to have symptoms of depression, anxiety, or ADHD" (Ferro et al., 2016, p. 535). Findings also indicated that adolescents with food allergies demonstrated increased risk of persistent symptoms of depression compared to the no food allergy group. The authors suggest this might be due to the stress associated with having a chronic condition, the realization that food allergies are permanent, or the increased risk of being excluded by their peers.

Fox & Warner (2017) explored the under-examined relationship between food allergies and social anxiety in adolescents with the primary goal of comparing self-reported social anxiety in participants with and without food allergies. Participants included 849 adolescents, including 87 with food allergies, between the ages of 13-17. Participants were from two public high schools and they completed standardized questionnaires regarding social anxiety. Food allergic teenagers also answered questions regarding their food allergies. While no association between food allergies and social anxiety was observed, the researchers did find that boys with food allergies had greater social anxiety than boys without food allergies. The authors note that food allergic youth with high social anxiety might be more sensitive to parental worry and over control, which might lead them to over-report social anxiety. The findings of this study revealed that youth did not experience social avoidance related to their allergies, however, Feng & Kim (2019) note that in some cases, food avoidance can lead to social isolation; and this can produce an increase in anxiety related to the potential of future allergic reactions.

Allergy-Related Response from Others

As depicted in the above mentioned studies, quality of life in food allergic individuals is impacted in various ways. However, living with food allergies also produces responses from

others in one's environment, particularly from parents, family, friends, strangers and also peers who might participate in bullying.

Lieberman et al. (2010) aimed to determine the presence and characteristics of bullying in the experiences of food allergic individuals. Participants included parents of food-allergic individuals, food-allergic individuals, and caregivers of food-allergic individuals. A total of 353 final surveys were analyzed, with the highest age demographic being between 4-11 years old. Survey respondents included parents of food-allergic individuals, food-allergic individuals and non-family member caregivers of food-allergic individuals. Findings indicated that 24% of all participants had experienced bullying, teasing or harassment because of their food allergy. Other reasons for bullying included having to carry or wear their epinephrine injectors, having to sit away from the group during mealtimes, or receiving special treatment. Many of the bullying incidences took place in schools where perpetrators were classmates, as well as teachers and school staff. The consequences of bullying included sadness, depression, embarrassment or humiliation. Most importantly, participants reported specific physical acts of bullying behaviors that involved being touched by their allergen, having their allergen thrown or waved at them, and others intentionally contaminating their food with their allergen. All of these instances can potentially impose a life-threatening risk.

Feng & Kim (2019) reported two instances in the media where individuals with food allergies' lives were put at risk because they were specifically targeted by bullies. The first incident included a university student who intentionally smeared peanut butter on the face of their unconscious peanut allergic classmate. The second incident included a teenager who rubbed pineapple on her hand and intentionally gave a high five to an individual with a known pineapple allergy. In both these instances, the bullies pleaded guilty to assault and battery or felony aggravated assault and criminal conspiracy.

Food allergic individuals may experience anxiety regarding dating. Although there is little literature on this topic, Hullmann et al. (2012) compared dating anxiety, problems in social relationships and health-related quality of life, in adolescents and young adults with food allergies in comparison to their healthy counterparts. Participants included undergraduate students with self-reported food allergies and undergraduate students with no reported allergies or chronic illness history. Participants answered a demographic questionnaire, a dating questionnaire, the Dating Anxiety Scale for Adolescents and the SF-36 Health Survey

Questionnaire. The results indicated that adolescents and young adults with food allergies experienced more dating anxiety and fear of “negative evaluation”. The authors speculate that this anxiety may be due to the embarrassment they feel about having an allergy. Additionally, they may fear telling their partners about their allergy and the reaction they may receive. The results indicated that the majority of participants with food allergies reported “that their allergies interfere with physical intimacy with their current partner” (Hullmann et al., 2012, p. 172).

Participants in the previously mentioned study by Peniamina et al. (2014) discussed how social embarrassment and standing out made them feel as though they were a burden to others. Participants also discussed how other people’s lack of awareness was a concern for them by stating “they know I’ve got a peanut allergy but it’s like they can never remember. And they’ll bring stuff with peanuts in it and then they’ll tell me, ‘Just pick it out or just eat around it’. And I’m thinking ‘If something’s poison would you tell someone, ‘just eat around the poison? Just take it out of the poison?’” You know? And that just gets me” (Peniamina et al., 2014, p. 940). Participants also discussed how the lack of knowledge from others often came across as being met with rude or judgmental comments. This lack of awareness, especially among restaurant staff, could lead to accidental allergen exposure as one participant stated, “They didn’t know couscous had gluten in it. Made me wonder what else they didn’t know” and “ ‘Oh no, it’s got no nuts in it, but we’re just gonna use a peanut oil over the top’ That could kill someone” (Peniamina et al., 2014, p. 940).

Music Therapy and Health-Related Anxiety

The previous section explicates literature that documents food allergy-related anxiety. Music therapy as a helpful support for people experiencing anxiety associated with varying medical diagnoses is increasingly documented in the literature. Food allergy, as a medical diagnosis with lifelong implications, shares sources of distress with different health diagnoses. Therefore, this section begins with a brief discussion of music therapy and anxiety before moving into how individuals are supported by music therapy in situations that, like food allergies, produce anxiety connected to fear of the unknown and specific intervention procedures. Individuals with food allergies undergo various forms of testing to confirm the presence of an allergy. The most common is the skin prick test, where “a small drop of the allergen is placed on a person’s arm or back. The skin is then pricked with a special needle, so the body can absorb the allergen” (Food Allergy Canada, 2024). Based on the reaction of the skin that has been pricked, a

food allergist will then determine if the reaction is positive or negative. According to Food Allergy Canada (2024), when an individual is allergic to a specific allergen, their immune system creates antibodies called IgE (immunoglobulin E). A second form of allergy testing includes blood tests, where an allergen is mixed with a blood sample. The level of IgE is then measured, and this determines whether or not an allergy is present (Food Allergy Canada, 2024). The third way to determine a food allergy is through an oral food challenge (OFC) which “comprises the oral administration of the suspected allergen in a controlled and standardized setting” (Calvani et al., 2019, p. 1). These tests can produce physical discomfort, and they can also generate anxiety about test results and fear of the unknown consequences of an allergy diagnosis.

Music Therapy, Anxiety and Depression

Gutiérrez & Camarena (2015) describe generalized anxiety disorder (GAD) in patients as a “substantial reductions in quality of life and deteriorated functionality” (p. 19). In this pilot study by Gutiérrez & Camarena (2015), the authors proposed music therapy as an approach for generalized anxiety disorder (GAD) – a diagnosis that shares some symptoms with food allergy-related anxiety. Their study explored whether music therapy could reduce anxiety levels in patients with generalized anxiety disorder. It also examined whether music therapy could reduce depression levels in patients with GAD. The treatments were divided into receptive (pre-recorded music) and active application (music therapist and patient engaged in music creation). Treatment consisted of 12 two-hour structured sessions with the major methodological steps including: identification of a theme, preparation, exploration, contact and intensification, resolution and processing. Results indicated that music therapy reduced Beck Anxiety Inventory and Beck Depression Inventory scores for the participants receiving pharmacological treatment, therefore showing the effectiveness of music therapy to reduce depression and anxiety levels for participants with GAD. Interestingly, the patients noted that the psychotherapeutic process helped them in the areas of empathy, security, and self-esteem. They also stated that the alternative tools could be used in moments where they felt stress and anxiety, which in turn could allow them to manage conflict and reduce anxiety

Food-allergic individuals, as cited above, can live with a fear of dying, even if their actual circumstances differ from patients receiving palliative care. Horne-Thompson & Grocke (2008) examined whether a single music therapy session could reduce anxiety in terminally ill patients – anxiety that literature suggests may also be experienced by food-allergic individuals who fear

contact with a life-threatening allergen (Avery et al., 2003; Bacal, 2013). A total of 25 participants between the ages of 18-90 years with end-stage terminal disease participated in the randomized-controlled trial. Those in the experimental group received a single music therapy session which lasted between 20-40 minutes with a registered music therapist. Music techniques included playing live familiar music, singing, music and relaxation, music and imagery, improvisation, music assisted counselling, reminiscence, and listening to recorded music. In the control group, a volunteer sat with the patient and offered non-musical activities. The results of the study supported the idea that music therapy is effective in managing anxiety in patients who are terminally ill. A post hoc analysis found reductions in pain, tiredness and drowsiness.

Gallagher et al. (2006) examined the effects of music therapy in palliative medicine with patients with advanced disease. Music therapy sessions were conducted with a board-certified music therapist or music therapy intern. During each session, patients were assessed to determine treatment goals. Once those goals were established, the therapist used a variety of interventions such as live music listening, singing, musical life review, songwriting, instrument playing, verbal processing, etc. Before and after each session, patients completed the Rogers' Happy/Sad Faces Assessment Tool. A behavioral scale was also used by the music therapist to assess facial expressions, body movements, sleep, and verbalizations/vocalizations. Results of the study indicated that symptoms such as anxiety, depression, pain and shortness of breath had improved after music therapy interventions. Furthermore, there was no statistical difference between patients with or without music training thereby suggesting that music therapy could be of benefit for anyone, regardless of their musical background or experiences.

Jasemi et al. (2016) conducted a quasi-experimental study on the effects of music on cancer patients with anxiety and depression. Participants included 60 patients between the ages of 18-65 years old diagnosed with stage 1, 2, and 3 cancer. Baseline measures were taken using the Hospital Anxiety and Depression Scale (HADS) 24 hours prior to intervention. Patients then listened to relaxing light music (sea, rain and water sounds) for a minimum of 20 minutes per day, for 3 consecutive days. At the end of each day, the HADS questionnaire was administered. The results showed that music therapy was effective in decreasing depression and anxiety in patients with cancer. It is important to note that the authors in this study used the term music therapy instead of music medicine, even though there was no board-certified music therapist

involved in the study. This therefore suggests a need for the intentional integration of Certified Music Therapists in studies that claim to examine the use of music therapy.

Music Therapy and Procedural Anxiety and Pain

Food allergic individuals may not undergo surgical procedures related to their diagnosis, but they often undergo allergy testing and take medications to both determine and treat their allergic condition. Giordano et al. (2020) evaluated how music therapy could be used as a non-pharmacological method to reduce preoperative anxiety (and compliant behavior during anesthesia) in children aged 2-13. The control group, comprised of 19 patients, received standard care. A total of 29 patients underwent a 15-20-minute music therapy session in their hospital room prior to their procedure, with the frequency of sessions ranging between 1 and 6. A certified music therapist used active and receptive therapeutic techniques. Participants listened to music with headphones or audio speakers. The music therapist then accompanied the patient to the operating room. Music therapy support was offered while the sedation was administered, and the music therapist stayed in the room until the patient fell asleep. Data was measured using the Modified Yale Pre-operative Anxiety Scale (m-YPAS). In addition, the medical staff completed a questionnaire containing 6 questions. Results indicated that the music therapy group showed lower preoperative anxiety scores in comparison to the control group. The authors support the efficacy of integrating music therapy with pharmacological approaches in order to reduce anxiety in children who are undergoing invasive diagnostic procedures. The authors note that music therapy was integrated within patient care throughout the entirety of the preparation process. This leads patients to enter the operating room without fear, more quickly and more independently.

Zengin et al. (2013) evaluated the effect of a music intervention on stress hormones, physiological parameters, acute procedural pain, and anxiety before and during port catheter placement procedures (PCPPs) in a prospective, randomized controlled study on 100 oncology patients with ages ranging from 19-75 years. The music intervention group listened to music from the moment they were brought into the surgical room until the procedure was completed. Participants filled out the State-Trait Anxiety Inventory (STAI) scale on arrival and after the procedure. Researchers assessed the effects of music on serum cortisol and adrenocorticotrophic hormone levels, heart and respiratory rate, and systolic and diastolic blood pressure, on arrival, immediately prior to and immediately after the PCPP. Pain and anxiety scores were examined

using the Visual Analog Scale (VAS) and State-Trait Anxiety Inventory scale. Results indicated that music intervention decreased anxiety and pain scores in the experimental group when comparing to the control group. Results also indicated reductions in hormone levels, heart rate, respiratory rate, systolic and diastolic blood pressure immediately prior to and immediately after the PCPP, in patients in the music treated group compared to the control group. The authors note that “music can also act as a mental attention-distracting device via the modification of the transmission of pain impulses; a stimulus of music may mask unwanted pain stimuli via distribution of attention” (Zengin et al., 2013, p. 694).

Kim et al. (2011) investigated the anxiolytic effects of music intervention on patients undergoing impacted mandibular third molar surgical extraction. The control group consisted of 113 participants. A total of 106 participants were in the music treatment group where they listened to pre-selected music from the moment they arrived in the operating room until the completion of the procedure. Corah’s Dental Anxiety Scale was used to assess preoperative anxiety, the Dental Anxiety Scale was used to assess intraoperative anxiety, the Visual Analog Scale was used to assess perioperative anxiety. Intraoperative and postoperative pain was also recorded. No differences were found in blood pressure between the experimental and control group, however patients in the music treated group had significantly less intraoperative anxiety than the control group when controlling for preoperative anxiety levels. Additionally, the music group showed smaller changes in heart rate in comparison to the control group.

Nguyen et al. (2010) examined whether music medicine would influence pain and anxiety in children with cancer who were undergoing lumbar punctures (a painful cancer treatment procedure). The randomized clinical trial included children aged 7-12 years, diagnosed with leukemia who were undergoing a lumbar puncture. To analyze pain scores, participants rated their pain before, during and after the procedure using the Numeric Rating Scale (NRS). To analyze anxiety scores, the short Spielberg State Trait Anxiety Inventory scale (STAI) was used before and after the procedure. Data collection began immediately prior to the procedure, by evaluating heart rate, blood pressure, oxygen saturation, respiratory rate in addition to the pain and anxiety scores. These categories (other than the anxiety score) were recorded and monitored during the procedure while some children listened to music, and others did not. The short STAI was administered once the procedure was complete and the participants were then interviewed. The results showed lower pain scores, heart and respiratory rates in the music group, before and

after the procedure. Anxiety scores were also lower in the music group during and after the procedure. Children in the music group stated that listening to their favorite music allowed them to feel calm and relaxed and also helped them take their mind off the potential harm of the procedure. They also stated that they felt less pain compared with other procedures they underwent with no music. The children in both groups stated that they wanted earphones for their next procedure. The final results indicated that anxiety scores were lower in the music group before and after the procedure.

Music Therapy and Fear of the Unknown

Literature cited above points to fear of the unknown consequences of contact with an allergen. While literature that explores music therapy as a support for this specifically-focused fear appears non-existent, adjacent studies offer useful strategies to address this very real concern. Rossetti et al. (2017), conducted a randomized trial by examining the use of music therapy on anxiety and distress during simulation with patients diagnosed with head and neck or breast cancer in a sample of 78 patients. Patients completed the pre-State Trait Anxiety Inventory (STAI-S Anxiety) in addition to the Symptom Distress Thermometer (SDT). Patients in the music therapy group received a consultation with the music therapist to discuss which pre-recorded songs they wanted to have played during the simulation. Patients also participated in a 20-minute individual music therapy session where the music therapist played improvisational music in D Mixolydian mode to enhance entrainment and help induce relaxation. The music therapist used specific therapeutic techniques which patients could use on their own during the simulation procedure. The control group did not receive music therapy. Results indicated that music therapy lowered patient anxiety and distress during the simulation procedure. The authors note that the goal in decreasing emotional distress during the simulation procedure, was to hopefully decrease the amount of trauma experienced by patients during their first radiation therapy treatment.

Conclusion

The above literature outlines the various ways in which food allergies can impact quality of life in food allergic individuals. These impacts were seen through allergy-related daily necessities, allergy-related fears and allergy-related responses from others. Although there is no detected literature on the use of music therapy to address anxiety related to food allergies, there is evidence on the use of music therapy to address health-related anxiety. Specifically, music

therapy was used to address anxiety and depression, procedural anxiety and pain, and fear of the unknown. Although individuals with anxiety related to food allergies do not live the same reality as those with anxiety regarding other health conditions, there are certainly links that can be made between both groups – links that provide insight into how music therapy might be used to support food-allergic individuals.

Chapter 3. Methodology

Design

This thesis uses a heuristic self-inquiry methodology (Moustakas, 1990). Six phases of heuristic inquiry, as articulated by Moustakas (1990) were conceptualized to align with the purpose of the present study and used to collect and analyze the data. Moustakas (1990) describes the heuristic process as “a way of being informed, a way of knowing. Whatever presents itself in the consciousness of the investigator as perception, sense, intuition, or knowledge represents an invitation for further elucidation” (p.10). This methodology was chosen as a means of positioning myself as the sole participant. Moustakas (1990) notes that the Greek word for heuristic is to discover, thus, making the purpose of this process one of self-searching, self-dialogue and self-discovery. Therefore, the hope for this methodology was that it would allow me (the investigator) to uncover areas of insight that I have not yet explored.

Validity

According to Moustakas (1990), “the question of validity is one of meaning” (p. 32). Therefore, the researcher is the only person who can make that judgement because they are the only one who has experienced all six phases of the methodology. Throughout the self-heuristic process, the researcher is the one who is continuously checking to see if their experiences and data have resulted in their true meaning. Moustakas (1990) states that “the heuristic researcher’s ‘constant appraisal of significance’ and ‘checking and judging’ facilitate the process of achieving a valid depiction of the experience being investigated” (p. 33). In order to ensure validity throughout this process, I (the researcher) intentionally took the time to reflect throughout the songwriting and data analysis process in order to make meaning from my lyrics. In addition, further reflection and discussion with my supervisor allowed me to repeatedly consider the meaning of my data, thereby ensuring its validity.

Materials

The main materials used in this research were my piano, my guitar and my voice for the songwriting process. My notebook and writing instruments to write prompt responses, song lyrics and response journals. My cell phone for recording my songwriting sessions and my laptop for researching literature and typing thesis chapters.

Delimitations

A main delimitation in this project is that the entirety of my written songs (in both audio and written format) were not shared. The reason for this being the abundance of data and the deeply personal nature of the songs. Instead, Chapter 4 will specifically focus on the main themes that emerged in the songwriting process, while highlighting specific song lyrics to further demonstrate my thought process.

Data Collection and Analysis Procedures

The first phase of heuristic research according to Moustakas (1990) is the *initial engagement*. During this time, the researcher is essentially taking the necessary time to understand and familiarize themselves with their topic while allowing space for self-reflection. The researcher must look within themselves for awareness and knowledge while immersing themselves within the topic in order to discover the meaning and formation of their research question (Moustakas, 1990).

During this initial phase, I took time to deepen my understanding of my topic. Although I have lived with a food allergy my whole life, I found it necessary to engage with the literature that documented the experiences of others who live with food allergies. This phase began in Fall 2022 and continued through Winter 2023 during the graduate research courses that supported the development of my research proposal CATS 691 (Research in the Creative Arts Therapies), MTHY 600 (Music Therapy Advanced Literature), and MTHY 693 (Research in Music Therapy). My topic and research questions were further refined in May 2023 until mid-June, 2023. During my topic-specific reading, I read, highlighted and wrote down key words and phrases that either resonated with me or that I found to be particularly insightful. In addition, I also read more about my specific methodology by reading more about Moustakas work.

The second phase was the *immersion* phase. Moustakas (1990) explains that “the researcher lives the question in walking, sleeping, and even dream states. Everything in his or her life becomes crystallized around the question” (p. 28). The researcher becomes intertwined with the research question, with the goal of furthering their knowledge and understanding of it. The researcher must be opened to allowing anything in their life (people and places) to become connected to their question as a form of immersion in order to focus their concentration. Moustakas (1990) suggests that self-dialogue and self-searching can further the immersion phase.

The immersion process began June 27th, 2023 and lasted until July 19th, 2023.

Songwriting was specifically chosen as the reflexive creative medium because it has been a helpful mode of expression in past experiences. Knowing that it had been a beneficial experience that had allowed me to explore my feelings musically, I assumed that it would be a helpful way to reflexively explore my feelings about living with a life-threatening food allergy. I engaged in songwriting two days a week, over a period of four weeks, and wrote a total of four songs. Each song explored a specific aspect of my experience of living with my food allergy, and a specific prompt was developed to inspire the songwriting session. The first prompt was broad and was derived from my primary research question. Each songwriting session produced new insights that I used to generate a new prompt for the following songwriting session. The four main prompts were as follows: 1) In general, how do you feel about having a food allergy?; 2) How having an allergy affects me; 3) My allergies and my fears; and 4) How does having an allergy impact how I perceive my place in this world?

Once I had written a prompt, I began each songwriting session by freely journaling my response to the prompt. I wrote down everything that came to mind about my food allergy and associated feelings and experiences. This free journaling lasted between 15-30 minutes. I then began the songwriting process by using the journal entries as the inspiration for my song lyrics. As I continued the songwriting process, I played piano, sang different melodies and wrote new lyrics while keeping in mind my writing prompt. Each session was recorded on my phone because recording allowed me to re-listen to the melodies or chords that I had created. At the end of each songwriting session, I wrote in my journal to document my thoughts and feelings about the songwriting process. Journaling also allowed me to expand on certain feelings about my many emerging insights. These journal responses served as a primary source of data along with the song lyrics that were created. I dedicated two full days to each of the four songwriting sessions, with each session lasting two to five hours.

The third phase was the *incubation* phase. Importantly, according to Moustakas (1990), this phase is still a time of growth. Moustakas (1990) states that “incubation is a process in which a seed has been planted; the seed undergoes silent nourishment, support, and care that produces a creative awareness of some dimension of a phenomenon or a creative integration of its parts or qualities” (p. 29). Essentially, by shifting one’s focus to other matters, one becomes open to bringing into awareness other ideas.

During this phase, I took approximately three weeks to step away from my research from July 20th, 2023 until August 10th, 2023. The majority of this time was spent traveling with my husband. This time was incredibly enriching on a spiritual, mental and emotional level. Although I was technically taking a break from my research, living with an allergy does not allow for a break from associated daily realities. Given that I was traveling abroad to a country with new foods, navigating was difficult because my safety was an ever-present priority.

Moustakas (1990) describes the fourth phase, the *illumination* phase, as a “breakthrough into conscious awareness of qualities and a clustering of qualities into themes inherent in the question” (p. 29). This process also brings about new layers to our knowledge while also correcting past assumptions. Therefore, this stage allows the researcher to “uncover meanings and essences” (Moustakas, 1990, p. 29).

During this phase, in order to make new meaning from my data, I engaged in open, axial and selective coding. Data was generated in two ways; songwriting and response journals. In *open coding*, “you locate themes and assign initial codes in your first attempt to condense the mass of data into categories” (Neuman, 2014, p. 481). For this research, both my song lyrics and response journal entries served as my data. I first began by re-reading my song lyrics and response journal entries in order to start identifying main themes that stood out to me. I then went through all of my data once again and began adding my song lyrics into an Excel document. I then created broad descriptive (headings), and grouped song lyrics and journal entries (my data) under each heading. Each data entry was specifically color coded based on which song or journal entry they belonged to because this provided important context when looking at each code. *Axial coding* is seen as a ‘second pass’ through your data. This is when according to Neuman (2014), the focus is more on themes than on the data. During this phase, I tried to group together my headings to see what they had in common thereby reducing the number of headings. Therefore, the focus during this phase was less on the data itself, but more on what story the headings were trying to convey. The headings were then re-organized as themes under larger categories. These categories represented a larger story of each group of themes. *Selective coding* is described as “scanning all the data and previous codes, looking selectively for cases that illustrate themes, and making comparisons after most or all data collection has been completed” (Neuman, 2014, p. 484). During this phase, I re-organized my data in order to find the best way to tell my story, and find more commonalities within the

themes. I dug deeper to find the links within the data by re-organizing and re-naming some of my categories. In addition to changing the categories, I also re-grouped some of the themes. This final step of the coding process took place during the explication phase once I had a deeper understanding of my data.

In the fifth phase, the *explication* phase, the researcher begins to explain the meaning of the data. Moustakas (1990) states that the purpose “is to fully examine what has awakened in the consciousness, in order to understand its various layers of meaning” (p. 31). In this phase, new themes emerge and the researcher engages in self-disclosure to expand on the overlapping meanings and experiences. Once these different themes are organized, Moustakas (1990) explains that the researcher then compiles their work and pieces it together as a whole.

I began this phase in October 2023 by making links between the different themes by grouping them under categories. Several attempts at this coding were made in order to figure out how best these themes worked together to tell my story. It is worth noting that during this phase, some of the open coding I did at the beginning of the data analysis no longer applied. Therefore, the explication process allowed for a deeper understanding of my data by realizing that not all of them applied to their initial codes.

Moustakas (1990) sixth and final phase is the *creative synthesis*. In this final phase, once the knowledge has been illuminated and explicated, the researcher can partake in the creative synthesis. This can be through any creative medium such as poetry, drawing, painting etc. Moustakas (1990) explains that “knowledge of the data and a period of solitude and meditation focusing on the topic and question are the essential preparatory steps for the inspiration that eventually enables a creative synthesis” (p. 32). Furthermore, Moustakas (1990) explains that the researcher must move beyond the data and look inwardly on the research question, in order to express themselves. I engaged in the creative synthesis on January 9th, 2024.

Throughout the illumination and explication process, I began thinking about how this experience could be depicted in a creative way. Although this process will be further discussed in the final chapter of this thesis, the original idea came to me early on in the process. In the end, I decided that the most expressive way to engage in this process was through songwriting. Since this was such a valuable and insightful experience during the immersion phase, I knew that songwriting would allow me to express myself musically while being able to describe how this entire process has challenged and taught me.

Ethical Considerations

Given the introspective nature of this topic, it is important to note that this process was not meant to be therapy, rather the deep reflections and insights were made to be used for the purpose of research. Prior to beginning the songwriting, I planned to speak to family should any topic or theme become too overwhelming for me to handle. As the steps of the heuristic inquiry progressed, the content did not prove to be too overwhelming, therefore I did not require any additional support.

Chapter 4: Illumination and Explication

The primary research question explored throughout this project was: What insights might emerge when I, a new music therapist, engage in reflexive songwriting to explore my experiences of living with a life-threatening food allergy? The subsidiary questions were: 1) what insights, if any, will be related to experiences of anxiety? 2) what insights, if any, will be related to interpersonal relationships and support? And 3) how might these insights contribute to my music therapy practice?

The final coding is revealed in Table 1, listing the 3 main categories with their respective themes.

Table 1
Overview of Categories and Themes

Category 1: The Big Picture
Theme 1a: Who I am
Theme 1b: The Big Questions
Theme 1c: Society and Me
Theme 1d: Internal Desires and Hopes
Category 2: Additional Labour
Theme 2a: The Weight of Responsibility
Theme 2b: Guilt, Burden and Feelings of Doubt
Theme 2c: The Complexities of Tension and Confusion
Category 3: The Emotional Outcome
Theme 3a: Unexpected Anger and Frustration
Theme 3b: The Reality of Anxiety and My Fears
Theme 3c: Avoiding and Moving On
Theme 3d: Vulnerability and Unfairness

Category 1: The Big Picture

As I began the song writing process, I did not know what the data would ultimately contain. I mostly wondered how all of my lyrics would come together into different themes and categories. After much thought, analysis and several attempts at reorganizing my data, it became clear that there was content that indicated how much I was thinking about the big picture in life. The following section will explore the more retrospective thoughts regarding who I am, how I fit into and navigate the world, what my desires and hopes are, and some bigger and more meaningful questions that I have found myself pondering.

1a: Who I am

As I engaged with the data during the analysis process, I began to wonder about how much of who I am is shaped by the realities of my allergy. There are certain qualities I embody that feel quite characteristic of me, however throughout this introspective process I have asked myself... am I like this by coincidence/upbringing, or am I like this because of my allergy? This question surfaced in the lyrics of my first song which states *"I am over prepared, ahead of the game, proactive I fear for my sake"*. In general, these are three accurate ways that I use to describe who I am in general; over prepared, ahead of the game and proactive. However, I also see these traits very present in myself when managing my allergy. I must be prepared at all times and carry an EpiPen and Benadryl, always think ahead to ensure I research and contact accommodating establishments and I must constantly anticipate risks by ensuring I always have a snack in my purse. The question remains: Am I like this because of my allergy, or does my personality cause me to react this way in regards to my allergy? I further ponder by singing *"Who am I? Can it be? It's bled into who I am, it's part of my identity. I'm wired this way. The good and the bad. For all the reasons that I hate it I depend on what it's made of me"*. These lyrics were so meaningful for me because there is so much depth to them. I cannot separate myself from this integral part of who I am because it is so deeply engrained in me. Without it, I would not be the same person I am today. The behaviors that my food allergy has trained me to consistently deploy, have become part of my identity. Interestingly, they have bled into parts of my life that do not have anything to do with my allergy. It leads me to ask... Do I depend on my allergy to make me who I am? What version of Adriana would I be without it? I journaled the following regarding the above lyrics,

"The notion of my identity being tied into my allergy was very eye opening. This idea that even if I didn't have it, I wouldn't be 'special'. Like a love/hate relationship. The notion of it giving me validation perhaps? That it's almost like a dependency for my personality or identity?"

Who would I be without my allergy? It has helped shape so much of me since my childhood. It has impacted the way I view the world, how I interact with others and how I navigate my way through society. Part of this experience has also made me wonder whether I am a little too cautious or extreme at times. I journaled that *"My personality, identity and character as extreme and cautious as it may be, is what has saved me thus far"*. Therefore, if I was not so extreme,

proactive or prepared, perhaps I would have had many more life-threatening encounters. There is a possibility that if I wasn't so *me*, then perhaps I would not be here today.

This internal conversation about identity and dependence is strong because I do not know a life without constant food caution. Even though I can be critical of myself and my allergy, this process has made me aware of the significant tie between my identity and my allergy. As previously stated in my lyrics, it has "*bled into who I am, it is part of my identity*". I cannot escape it, and perhaps should not. It is part of who I am.

1b: The Big Questions

The songwriting process provided an important opportunity to explore some of the internal questions that I did not even know needed answering. Some of these questions came up in my writing and exemplified the uncertainty I experience regarding myself and how I handle my allergy. Essentially, this process made me question my stance when it came to asking myself such opposing, yet ever-present questions. My lyrics expressed, "*Am I paranoid or in survival mode?*". This question made me think about where I stand when it comes to these two potential extremes. Describing oneself as paranoid is not always a positive trait to have. However, perhaps it is not always detrimental, rather, it is just me being proactive and acting to ensure my safety. Therefore, this process revealed that part of my internal dialogue revolves around self-questioning and self-doubt, which I try to resolve by seeking certainty. Essentially, having an allergy means having to move through the world in the messy middle.

Another similar example of this internal dialogue is expressed in the following lyric "*I'm too extreme can I loosen the reigns? Sure, why not, but at what cost? My life?*". In this example, I'm clearly questioning whether or not I can lean towards a specific desired change. There is a small internal debate about whether or not I should continue to be so stringent when it comes to my allergy. However, I ask myself whether putting my life at jeopardy is worth the risk. Being extreme and loosening the reigns can be considered two extreme thoughts on a spectrum, and part of my internal dialogue includes figuring out where I fall. Do I continue being extreme in how I handle my allergy, or do I loosen the reigns?

One of the biggest questions I have asked myself in my lyric writing is "*Why me? Why not me? What good does this bring me?*". This is a question that I have asked myself many times throughout my life. I have always wondered what the greater purpose of being born with an allergy is, but I have yet to find the answer. As a person with faith, I have asked myself this question

through a Christian's perspective, in relation to my relationship with God. But then I ask myself, 'why not? What good would being born in a *perfect body* bring me? What about me specifically would exempt me from any type of medical *abnormality*?' Although I do not have the specific answers, I believe that leaning on my faith is essential. My lyric expresses "*when the ground beneath me shakes, I'll rely on my firm foundation. I can't control my fate. I'll call out to the one who made me*". Therefore, this question 'why me?' is really a question that is beyond me, beyond my knowledge and perhaps not an answer I will ever receive during my time here on earth.

1c: Society and Me

There are aspects of the outside world that shape how I view myself and how I act. For my final song, I responded to the following prompt: 'How does having an allergy impact how I perceive my place in this world?'. My lyrical response was "*I can't exist too much in a world not made for me. My place is determined by others who don't really know me, they threaten my safety. Not guaranteed I belong somewhere*". Essentially, whether I fit in or have a place in society is dependent on other people. To explain, I journaled the following "*Whether or not I can occupy or share a space with someone is based on what they decide to eat. That's wild. Food and other people determine my space in this world*". If someone next to me in class decides to eat a peanut butter granola bar, I no longer feel that I am welcomed in that space. Whether or not I can occupy a place is dependent on another person. That feels shocking, the notion that my sense of belonging and ability to participate in society are unpredictably in the hands of others.

I also discovered through this process, that I tend to believe I must always find the positive in what can be a difficult existence at times. As someone who tends to look at the positive things in life, I have also brought this tendency into how I view my allergy. In general, even when I am confronted with challenges in life, I choose not to dwell on them. This process left me wondering why I do this. During my songwriting process, in the midst of discussing the challenges of feeling that I do not always have a safe place in this world, I wrote "*I'm not completely ostracized, I'm grateful that I live this life*". Where does this need to look at the positive come from? Is it because I have been told by outsiders things such as 'at least you're only allergic to peanuts and not the other allergens' or 'it could be worse'. So often, the uncritical comments of others lead me to believe that I have to find the positive, even when an unfair circumstance arises. Comments such as "it could be worse" or "at least you only have one allergy" are phrases that I often adopt. These points are valid and often times essential to

consider in order to keep from dwelling on the negative. However, this process has shown me that it is okay to acknowledge my own reality at times, without adding any sort of positive spin to it. As long as one does not become consumed with negativity, exploring the difficult sides can actually become very enlightening and freeing.

This insight has shown me how I could help future clients in my music therapy practice. Instead of invalidating feelings and focusing on the positive all the time, as a music therapist it is important to acknowledge the reality and feelings of our clients. Sitting with the discomfort and validating that sometimes one's reality is not *fair*, can be beneficial. Perhaps certain individuals have never had their feelings validated, and simply agreeing with them can allow them to feel heard and understood. However, it is important to not dwell on certain feelings. Therefore, this insight has shown me that acknowledging feelings are valid and helpful for our understanding, however moving forward from them is what is also important.

Another very surprising, yet recurring theme in the data was the concept of 'standing out'. Having a food allergy means that I am often very visible within society, even when I simply just want to blend in. One of my lyrics expresses "*On a stage for everyone to see me*" and "*Put in a box while they all stare and watch*". Sometimes I feel as though everyone around me feels entitled to have an opinion about me, as though I was a character on a stage for others to have an opinion about my allergy. For example, if I'm sitting at a social event and not eating because there is nothing safe for me, I suddenly become the focus of attention and topic of conversation. I later journaled about wanting to fly "*under the radar*". As someone with an allergy, it is imperative that you stick out in society for your own safety, whether that be talking to a restaurant server or having a flight attendant ask other passengers to refrain from eating peanuts. Although standing out is essential for my health, it is not a feeling that I enjoy since I would much rather blend in to society. Therefore, there is a very strong association between standing out and vulnerability (which will be discussed at a later point in this chapter).

The feeling of always standing out means that my sense of belonging sometimes feels jeopardized. This is expressed in my lyrics "*I'm never fully on the inside. One foot in and one foot out. Body and mind never fully immersed*". It seems that no matter where I am, most of the time I can never be one hundred percent like others in a social setting. There is always a part of me that is teetering on being fully included and fully excluded. Even when I try to blend in and be like others, there is always a part of me that must be aware of my surroundings and be

vigilant, because an unexpected danger can appear at any moment. I can be at a wedding and eat all the food I want and as soon as the dessert is served, bam! I'm back on the outside. Although these seem like trivial things, it further shows that there is always a part of me that is never completely 'all in', as I am always on guard.

I further express in a song lyric "*I'm living as the exception. Never the rule in a game that makes it hard for me to win first place. When there's no place*". Essentially, the world is not inherently constructed for someone with a life-threatening allergy and it is up to me to find ways to navigate a world that is not made for someone like me. Therefore, I am not the rule to the game, rather, I am the exception who is often confronted with unexpected hurdles. In my lyrics I express "*I freeze, life feels like a movie. Everyone else living their life. While I'm stuck in my head wondering how to survive*". I later journaled the following regarding these lyrics, "*It's like things are happening and you're just stuck in a bubble trying to survive and make your next move. Or like a one-way mirror, you see everyone just living and they don't realize you're on the other side watching, analyzing, and figuring out what to do next*". These feelings usually come about when I'm confronted with immediate danger. Something as harmless as someone eating chocolate, makes me freeze. In these moments, while everyone else is uninterruptedly living their life, I am internally planning on how best to proceed. At the same time, life is still going on and happening, and I'm on the outside observing, planning and nobody is even aware of the internal dialogue in my mind.

1d: Internal Desires and Hopes

As I engaged with my song lyrics, it became very clear that there were deep desires for an uncomplicated life, one where failure to think twice would not threaten my very existence. In one of my song lyrics I express "*I want to float not navigate, swim not jump through hurdles*". This lyric expresses a deep desire to live a smooth life. When living with a food allergy, there are often obstacles that make going about life complicated. This includes calling an airline ahead of a flight, doing extra research before travelling to a new country, speaking to a restaurant manager before going to eat at a new restaurant, and always making sure to leave the house with a snack in case I cannot eat at an event. These small acts add a level of complexity to my life, and they also add an extra layer of labour to the routine acts of living. I simply cannot just float through life like I perceive many others can, because there are often extra steps that I must take when I enter most public spaces. This idea is also expressed through the lyrics "*I deserve to live freely*" and "*I wish*

I didn't have to think twice". These two lyrics came about in the ending of my final songwriting session as I was responding to the prompt "*How does having an allergy impact how I perceive my place in this world?*". Essentially, my response is that I cannot live freely within this world, I not only have to think, but I need to think twice. This idea demonstrates that there is a sense of caution that is always lurking for those who live with a food allergy. One has to ask themselves 'do I have my EpiPens? Is this safe to eat? What is the person next to me eating? What is that smell?'. When having to be on high alert and aware of your surroundings, there is a sense of freedom that is taken from you. When one has to plan their move and cannot be guaranteed a safe place to eat when they are out, one is naturally forced to 'think twice' because they must be ready and prepared for all circumstances. For example, making sure to pack an extra EpiPen when I am going to a new restaurant for the first time or being worried about my EpiPens going bad when I am outside in the heat for too long. Another example is noticing that someone around me has eaten peanuts. In this scenario, I must then be aware of the surfaces that they have touched with their allergen contaminated hands in order for me to avoid touching the same infected surfaces. This is where the concept of *freedom* comes into play, because when living with a life-threatening food allergy, your life is a gift and too much freedom can be detrimental. So when I desire freedom, it is that I wish for a life where one wrong move does not threaten my existence- a life that isn't defined by the need for hypervigilance.

While these inner desires and hopes feel integrally connected to the anger I will explore in a latter section, this process allowed me to connect with them apart from anger and frustration. Within my anger and frustration lyrics, I discovered there were underlying desires and hopes. Interestingly, these two themes somehow coexist alongside one another. My song lyric expressed, "I WANT TO BE, FORGET ABOUT ME". During my data analysis, this lyric was originally coded within my anger category, but upon reflection, I asked myself 'what is it that I want?'. Clearly there is a desire for *something*. Is it to be like most people? To blend in? ... What is it? Perhaps this desire is so strong that it has no other way to be expressed other than in such an intense emotion; anger. It is further expressed in my lyric "*Everybody else cares, I don't want them to care!*". In this lyric, anger and frustration are the obvious emotions, however what do I mean by expressing that I do not want others to care? I believe that indirectly, I am uncovering this desire of not wanting to stand out. Maybe if other people 'didn't care' or pay attention to me, then perhaps my allergy would not feel so real and I would not have to be confronted with the reality and the

potential outcome of a mistake. Therefore, there is anger intertwined once again with a desire of wanting something specific, something that I cannot attain. This discovery was quite an interesting one, as perhaps the anger felt is so strong that I am desiring something so far off from what I am used to. The anger is rooted in the reality of my allergy, which I automatically associate with limitation. My desire, on the other hand, is rooted in the opposite of what I currently possess. Therefore, when anger is expressed, it is a cry for something different - a desire to move beyond the feeling of 'I cannot' towards 'I want'.

Category 2: Additional Labour

As stated above, living with a life-threatening food allergy means dealing with layers of complexity, such as packing your own food for events/trips, having to repeatedly explain your allergy to others who might not understand the severity of it, or making sure to have your EpiPen at all times. Therefore, there is a great amount of additional emotional and cognitive labour associated with food allergies. This emerged in my data as the added responsibility of keeping myself safe and keeping others comfortable, the additional feelings of guilt and burden that I often live with, and the complexities of tension and confusion experienced as a result of my internal dialogue.

2a: The Weight of Responsibility

As someone who lives with a life-threatening allergy, it is my responsibility to be in control of it. For example, when it comes to traveling, I need to ensure that I have packed the necessary food I need, that I have the right medication I need, and that I am cautious about what I eat. It also feels like it is my responsibility to make certain that others are not worried about me. There are times in social settings where I feel unsafe consuming food that has been offered. The nature of my reaction in these situations inevitably dictates how those around me react. If I become upset or appear anxious, those around me will not enjoy their time. I journaled, "*If I'm 'okay', everyone else is 'okay'. If I panic, everyone else panics. It's like even when I'm the one hurting, I have to keep it cool for others*". Basically, I am responsible for ensuring that my allergy does not get in the way of other people living their lives. If I am sad that I cannot eat a very delicious looking dessert, I do not let it show. I have learnt that when it comes to my engagement with others, I am responsible not only for my safety, but also for their comfort with my reality. I sang "*Say it's okay, I reassure them all. While my heart's heavy*". Even though in

the grand scheme of things, not eating a dessert is insignificant, the lack of freedom and inability to eat whatever I want without thinking can be frustrating.

Furthermore, when there is heightened potential for real danger, I feel a sense of responsibility for everyone around. For example, if I am in an airplane and someone begins to eat an item with peanuts, my mind immediately thinks of the following scenario; ‘if I have an allergic reaction everyone around me will panic. The pilots will have to make an emergency landing. This will be a great inconvenience to all the passengers who have places to be. I am going to make the flight attendants and pilots panic. My family will worry about me’ and so on and so forth. Although these seem like extreme thoughts, they are all very real and possible outcomes. To ensure that none of them become reality, it is my responsibility to do what I can do to prevent anything like that from happening. Since I feel such a weight of responsibility, I also experience an immense amount of guilt for having an allergy.

2b: Guilt, Burden and Feelings of Doubt

Since my sense of responsibility is so strong at times, a great deal of guilt is tied up with these feelings. Even though others might not agree, there are times where I feel as though my allergy is a burden to others. In these instances, I feel that it is my responsibility to occupy less space and take a step back so that I am not too noticeable or too much of a burden. I explored this idea in my song, “*Stress everybody else out, because I’m ‘special’, I don’t want to be ‘special’*”. For example, anytime someone cooks for me I feel a sense of guilt because I know that they pay extra attention to ensure that it is safe for me to eat. Similarly, when someone calls a restaurant to make sure I can eat there, I feel like a burden. I journaled the following “*makes me feel bad to ever know someone is paying special attention to me, or being stressed or inconvenienced*”. Although I have never been told that my allergy has been perceived as a burden to anyone, it feels additionally burdensome because I am always receiving extra attention when it comes to food. Even still, I journaled how I still “*feel guilty for being who I am and taking up space*”.

It always feels as though there is a layer of inconvenience for those who spend time with me in certain situations. For example, when traveling, it becomes important to frequent specific restaurants that I know have safe foods for me to eat. This can seem ‘boring’ which leads me to feel guilty perhaps because those around me may not want to eat at the same place three days in

a row. Even though it is what makes me feel most comfortable and safe, I still at times feel a sense of guilt.

In certain scenarios, my safety feels burdensome. This feeling is entirely self-imposed since I am surrounded by incredibly supportive friends and family who do not make me feel like a burden. However, this is an inevitable feeling in certain instances.

My feelings of guilt also emerge in circumstances where people make a clear effort to keep me safe, but I cannot be sure I can trust the safety of the food or location. This isn't self-imposed guilt with no grounding in reality. It comes from experiences of people saying something is safe yet still having the potential to harm me. For example, if someone makes a dessert and says 'there are no peanuts', this does not necessarily mean that I trust them as they may not understand my allergy or the risk of cross contamination. I then have to make up an excuse by saying 'I'm not hungry', or 'that's okay I've already eaten'. This usually makes me feel anxious but also guilty because I know deep down I need to do what is necessary to keep me safe. However, I do not want to offend anyone. This process has shed light on the complexity of the feelings of guilt and imposition that I sometimes experience. Therefore, the feelings of guilt have different layers as they are sometimes self-imposed and other times they can be imposed by others.

I also felt guilt while engaging in this whole project. By having these feelings, writing these words and singing my lyrics, I was (and am) afraid that those who read them will feel hurt. I'm so grateful for the amazing people in my life who I know love and care for me so deeply and who always want to help me. I journaled the following

"Part of me felt scared, nervous that anyone in my life will know about these feelings ... it's a hate but need feeling, where I know it's good for me, I know it's necessary and appreciated, but ... makes me feel bad to ever know someone is paying special attention to me, or being stressed or inconvenienced. That's why I just want to be".

There is also guilt associated with writing these songs and making this whole process about me. It makes me doubt my own feelings and makes me feel guilty for uncovering all of these emotions. I explore these feelings of doubt as I journaled:

"There's a part of me that feels like maybe I'm exaggerating and making it a bigger deal than it is. I guess that's part of the guilt because I have so much to be thankful for. Like c'mon Adri, don't be a victim. Or perhaps I'm being dramatic for the sake of the song? Here I am doubting

myself, typical. But I remember that these are the words I wrote when responding to the prompt”.

Since I have discovered so much about myself throughout this process, it makes one doubt whether these feelings are even true, or perhaps I am being overly dramatic and sensitive. I also express in my lyrics, *“Is it all in my head, how do I react?”*. Often times, I turn nothing into something. If I hear a food wrapper or smell a strong food odor, I begin to worry. I ask myself whether someone is eating peanuts around me or perhaps it is something I am imagining. If so, how do I move forward in that moment, if not, do I worry needlessly? Part of the guilt and overthinking naturally leads me to doubt myself and my own reality.

In addition, the doubt leads me to feel guilty about making my allergy such a big deal when in reality, these are not feelings that I experience on a daily, weekly or even monthly basis. These are accumulations of small instances and feelings that have slowly been gathering in isolated moments throughout my life. I express in my journal how *“part of me felt guilty for feeling so upset, as it’s not in my nature ... it felt liberating to be angry, but I still felt guilty. Guilty for not wanting others to help”*. Even when I am acknowledging the benefit of expressing myself, there is still an underlying feeling of guilt ... perhaps because I have avoided and pushed aside these feelings for so long, that acknowledging them feels surreal and out of the ordinary.

2c: The Complexities of Tension and Confusion

As I dove deeply into the process, the data analysis surprisingly evidenced how I often expressed two opposing views that nonetheless coexist in my thinking. Thereby bringing to light various areas of tension and confusion that I now realize are often in the forefront of my mind. On the first day of the immersion phase, I responded to the following writing prompt *“In general, how do you feel about having a food allergy?”*. Given that this was the first time I thought about this question, several thoughts ran through my mind. The beginning of my writing process revealed tensions I had not previously recognized. Primarily, the tension that surfaced had me moving between considering benefits and drawbacks of having an allergy. The opening lyrics of my first song expressed *“I’m confused, part of me, sees a blessing and a curse, two worlds I must traverse”*. This tension regarding the positive and negative aspects of living with my allergy is quite present throughout my first song, as I begin listing all of the reasons why having an allergy has benefited me throughout my life. For example, it has allowed me to appreciate my overall health and to truly value my life. Most importantly, it has allowed me to

look at what is important in life especially when in social situations. For example, when I am unable to eat in a social setting, I focus my attention on being with others and having conversations. However, as the song continues, I begin to lean into the reality and the difficulties of living with a life threatening food allergy. For example, the potential of death, the anxiety associated with having an allergic reaction, being over-prepared and overly cautious. This contrast between the first portion of the song and the second portion clearly depicts the ever present internal tensions that I was uncovering during the song writing process. Since I live with two opposing narratives, it often times leaves me feeling several emotions at once. This tension is expressed towards the end of the song as the lyrics ask “*How do I feel? I feel it all. This is simply my life I shouldn't complain at all. How do I feel? I feel it all. I'm hurt, I'm angry, I'm scared, I'm happy, I'm blessed... I'm alive*”. These lyrics show my constant movement between contrasting feelings, where I find myself moving in my mind between what I should feel, what I truly feel and what I do not necessarily want to feel. These tensions understandably lead me to feel confused- it is difficult to constantly live with these opposing feelings and the tension that their coexistence creates.

Once I completed my first song, I spent some time journaling the process and the new discoveries that came to light. I discuss the clash between two conflicting desires; the tension between needing other people's involvement, yet not wanting their help at the same time. My journal entry reads “*Even though I don't want it, I do want help. I need help. But part of me says NO! LEAVE, FORGET about it*”. I know that help from others is important, for example, letting me read ingredients contained in the food they have made, or being accommodating about the kind of restaurants we attend. However, sometimes it feels like I am so special and different, that I just want to disappear or end the conversation about my allergy. The guilt can feel so strong that the fact that someone is taking the time to help me, makes me feel so exposed.

Another tension that emerged from the data relates to my desire to live my life a specific way while also realizing the danger that doing so would inevitably provoke. My song lyric expresses “*I'm too extreme, can I loosen the reigns? Sure, why not, but at what cost? My life?*”. Therefore, the tension between desire and self-protection is often times a very real and present struggle that I am faced with. My song lyric expresses “*Well if I was reckless took more chances. Life would be more simple, and it wouldn't define me. I can do whatever but at what cost? My life? My safety? A double-edged sword*”. Therefore, this tension demonstrates the desire of

wanting to be a certain way, but having to be grounded in the real implications of such a decision. When weighing the options, perhaps the notion of freedom does not outweigh the value of my own life. Although the tension is always there, the majority of the time I err on the side of caution because living according to my desires will not lead to freedom, especially when the consequence is so definitive.

Category 3: The Emotional Outcome

In addition to the various mental and physical obstacles associated with food allergies, I also experience a variety of emotions in response to my lived experiences. Therefore, this section will explore the emotional outcomes of having an allergy, which are reflected in emotions such as anger, anxiety, avoidance and vulnerability.

3a: Anger/Frustration

As I sat down on the first day of the immersion phase to respond to my songwriting prompt, I was incredibly surprised by how much anger was flowing through me. I never expected these emotional moments as I am not generally someone who experiences anger very often. However, I was thoroughly shocked to see just how deeply I needed to express and feel this built up anger. I express the following in my song *“Everybody else cares ... I don’t want them to care! I WANT TO BE, FORGET ABOUT ME”*. This idea of others being so aware of my allergies and going out of their way to accommodate me is hard to accept because it makes my allergy all the more real. The more people care, the less I want them to care, and although that sounds ungrateful, it comes from a place of not wanting to be different. Part of me wants to be a fly on the wall, where nobody notices me or pays special attention to me. So when I say *“I WANT TO BE, FORGET ABOUT ME”*, it’s an intense feeling of just wanting to be *regular*.

I also journaled the following *“Maybe the anger comes from embarrassment? Am I embarrassed?”*. I wonder if I ever feel embarrassed about having an allergy, as if there is a giant sign over my head saying ‘peanut allergy, beware’. Perhaps this idea of being so different and having so much attention at times makes me feel embarrassed because I require special attention in comparison to others.

I also noted, importantly, in my journal that *“It felt liberating to be angry”*. This was the first time I gave myself the space to experience anger, and the time and space to *sit* with that anger. This was a very powerful and liberating feeling, however these moments felt unsettling since it was not an emotion I was very used to. This was also depicted as I journaled *“Part of me*

says *NO! LEAVE, FORGET* about it. *These are not feelings I've ever experienced before*". In the moment, I imagined myself in a social setting where the anger of having a food allergy was so strong that I needed to escape and not be present to witness just how deeply the attention and pressure of having an allergy affected me.

After the surprise and intense feeling of anger experienced during the first song writing session, I journaled the following:

"There was a build up of feelings inside that needed to be expressed. I didn't even know, it was like they were bursting to be said. I didn't realize the underlying feeling of wanting to just be, to be free. Not to be special. A sense of anger, and wanting to scream. I felt myself get emotional as I wrote the second half, as I was surprised and shocked at myself for feeling that way".

In this situation, my anger is rooted in a lack of freedom. As mentioned previously, my sense of belonging and ability to stand out are uncomfortable feelings that I experience, and in this situation, the outcome of these feelings is expressed as anger.

3b: The Reality of Anxiety and My Fears

Going into this project, I knew that anxiety was going to be a prevalent emotionally-oriented emerging theme. In all honesty, I thought it would be the only theme that would come up. Although anxiety regarding my food allergy has been present at moments throughout my life, I never dwelt on it because I would not allow myself to be overtaken by fear, especially in moments where it would be detrimental to my well being. The theme of anxiety was present within my first song. I wrote *"To always be on the edge, wondering if I'll fall"*. Having an allergy means that at any moment in time, an allergic reaction can occur. There is this sense of always waiting for the shoe to drop, wondering when you will fall over the edge because it can happen so easily.

Another very real and recurring theme within anxiety was the theme of death. It is a very real possibility for anyone who lives with a life-threatening food allergy. My lyric expresses, *"Then the panic sets in, I have a Kryptonite, I'm terrified, what if I die?"*. Knowing that there is a tangible object in the world that could easily kill me, can at times cause a great deal of anxiety. Because of this spontaneous and very real threat, my lyric expresses how I am *"On high alert, my guard is up I can't trust. Cuz the risk would be too much"* and *"Just when I think I am, I'm never safe"*. Being too comfortable is not an option for me, I need to be on high alert because a danger can appear anywhere. My song lyric further expresses this analogy as I write *"I live, with*

a magnifying glass like a detective looking over shoulders, trying to find the culprit of a crime". Having to always be on the lookout and analyze a situation can invoke quite a bit of anxiety. For example, being in an airport waiting to board a flight and noticing that someone has bought chocolate covered peanuts. In this moment, I instantly make a mental note of that person and wonder if they will be sitting near me on the plane. Therefore, this analogy of being like a detective looking over my shoulder is my reality, which in certain situations causes a great deal of anxiety.

This anxiety is also intertwined with fear since there are times where I do indeed fear for my safety. Such anxiety is heightened when being in an airplane, as I am aware that I am in a confined space, far away from help and where peanuts are much more present than they are in my daily life. In this particular case, my mind very quickly goes to the worst possible scenario... death. My lyric expresses the following, *"I'm not scared of death ... but I'm scared of dying. I'm afraid of how I'll feel"* and *"Will the air in my lungs flee with every breath that I try to take while they're closing in on me? Will I know the end is near, not able to do a thing?"*. I do not constantly focus on the possibility of death, but I am aware of what an anaphylactic reaction entails. Passing away from anaphylactic shock and the process of not being able to breathe is what I fear. This is especially true during times when I am in an airplane, or when I am far away from a hospital or medical help. I further sing about this idea *"Will I know the end is near, not able to do a thing"* and *"I fear, the lead up"*. Since I have never had an allergic reaction before, the unknown of it all is quite scary. I worry about whether or not I will know I am having an allergic reaction, and the way in which it will progress. I worry about whether my EpiPens will work, and how I will mentally handle knowing that the end is near and being helpless.

I also mention how *"I'm scared of what will save my life. The good outweighs the fear"*. Essentially, I am afraid of using my EpiPen. Although it is life saving and I never leave the house without multiple, there is fear associated with using such a large and loud needle. This fear might not be as significant in comparison to its benefit, but it is the reality. These thoughts do not come up in my daily thinking, however this songwriting process did resurface these strong fears that I do have in situations where I feel most vulnerable and at risk.

I later confronted a very challenging and emotional topic. My lyrics explore the notion of my passing in regards to my family members, *"How would others go on, if they lost a friend, a*

daughter, a sister and a wife? ”. I remember this portion of the song making me very emotional, and quite challenging to physically sing without tears. I journaled the following:

”Singing the part ‘if they witness my death how will they react?’ feels difficult. It’s hard to actually sing the words, I find myself skipping over it. Maybe it feels like I’m exaggerating or being dramatic. But it’s a possibility. It feels uncomfortable singing out loud. It feels too vulnerable. That’s probably one of the hardest things I’ve discovered so far, it’s hard to wrap my mind around that idea, and having to sing it out loud in such a vulnerable and emotional song makes it more real ... I never realized how much of an impact it would have on others. So even though I’m not scared of death, my death would impact others”.

These lyrics made everything feel so real, as I never thought about how my family and friends would handle my passing. It goes to show how having an allergy does not only impact the person living with the allergy, but their family and friends as well.

3c: Avoiding and Moving On

Living with an allergy means that at times, survival is your main focus. When you are in survival mode, there is no time to think about feelings and emotions. You simply make the right decision for yourself in the moment and move on. However, this process has made me discover and reflect upon the topic of avoidance. My lyrics express *“I don’t complain, don’t think about my feelings”*. As someone who is naturally quite a positive person, I am not one to focus on the negative. Whenever a situation regarding my food allergy comes up, I usually do not dwell on it and try to move past it. As my song lyric explains, I *“brush it off, no big deal”*. Perhaps because I know that dwelling on it would make me feel sad, brushing it off allows me to ensure that the focus is not on me. This, in turn, brings the attention back to whatever else is happening in the social setting. It is always much easier to push aside a feeling rather than confront it. I have often thought ‘what is the point of making it a big deal, just move on’. I then journaled about this explaining *“For someone who brushed off her allergies, I had no problem coming up with negatives. Those flowed right out of me”*. Essentially, when it came time to sit down and begin the writing process, I had no problem diving into the challenges and negative aspects of having a food allergy. Therefore, one would think that someone who never took the time to think about her feelings and always focused on the positive, would not have many deep feelings to uncover.

I further express, *“I want to feel, I’m allowed, but just move on”*. I believe this idea comes from me not wanting to ever feel bad for myself and make myself out to be the victim. I have so much to be grateful for, therefore, by complaining or feeling sorry for myself, I am making it a bigger deal than it has to be. However, there is another part of me that tries to tell myself that I am allowed to have feelings regarding my allergies. There are times in social settings where I also avoid my true feelings. For example, when not being able to eat the same food as other people. I express in my song, *“I let them know I’m fine. I don’t feel fine, not fair, I’m just left out”*. In front of others I make it seem as though I am perfectly fine. However, there are times where being so different can be hurtful, but again I do not dwell on it because, what good does that bring me?

Most of the time, I decide to move on because it is simpler to keep on living than to pity myself. Perhaps I actively or even unknowingly avoided engaging with these realities, because there is nothing I can do to change my situation. I will always live with my allergy.

Realizing how often I have avoided certain feelings regarding my allergy, made me question how this might be a feeling that is felt by others as well. In my future music therapy practice, I hope to allow my clients the space to further investigate and question their feelings, rather than avoid them. By confronting these avoided feelings and musically exploring their impact, this is where true progress can be made. Rather than internalizing experiences, there is a sense of freedom when bringing them to light, as this can allow for deeper understanding of oneself. Therefore, this new insight has shown me the benefit of confronting avoided feelings, and how this can impact potential future clients.

3d: Vulnerability/Unfairness

There is a sense of vulnerability and unfairness that is often associated with having a food allergy. Previously in this chapter, the theme of standing out in society was discussed. In this context, I sometimes feel exposed because others have access to what feels like very personal information. When the topic of my allergy comes up in a conversation or whenever I am being confronted with having to deal with my allergy, it is as if other people have an inside view of my life and are able to insert themselves into it. I explain this in a song lyric by expressing that I am *“Put in a box while they all stare and watch”* and *“On a stage for everyone to see me”*. In other words, having to explain my allergy to others while also having them comment on it, requires a sense of openness and vulnerability on my part. I also express *“Others they can see this ‘thing’*

about me. An invisible weakness, they can see right through me". This once again depicts how others can see an internal vulnerability so easily, and although it is important for others to know about my allergy, it does not negate the fact that a very personal part of me is being shared with others. It is something that I need to disclose about myself to others and strangers very quickly upon meeting them. When I have to share something personal with a stranger within the first few minutes of knowing them, this can feel very vulnerable. In general, most people do not share their medical history or life story within the first few minutes of meeting, however this is something I need to do to keep myself safe. Even though people care and come from a good place, it adds an extra layer of vulnerability because I feel so seen and so visible.

I also explored feelings of unfairness, as I express in my lyric "*It's not fair, no it's not. To carry a burden, for something so small to ruin me!*". There is a deep feeling of unfairness that I must live with, a burden associated with knowing that at any moment I can suffer the consequence of coming into contact with my allergen. This is a lot of pressure, and stirs up many emotions including frustration and anger. This unfairness is also explored in other themes throughout this chapter. The lack of freedom feels unfair. Having to stand out feels unfair. Having such a big responsibility and experiencing guilt feels unfair. The anxiety and fear I experience, also feels unfair.

Chapter 5. Discussion

The study's primary research question was: What insights might emerge when I, a new music therapist, engage in reflexive songwriting to explore my experiences of living with a life-threatening food allergy? The subsidiary questions were: 1) what insights, if any, will be related to experiences of anxiety? 2) what insights, if any, will be related to interpersonal relationships and support? And 3) how might these insights contribute to my music therapy practice? The sixth and final phase of Moustakas (1990) heuristic self-inquiry is the creative synthesis. Once the data has been analyzed and the researcher has made meaning of the experiences, they create material as a manner of self-expression. This chapter will also explicate limitations of the current study, personal, professional, and education implications and finally my closing thoughts.

Creative Synthesis

Throughout the immersion and explication phase, I began thinking about what I would do for my creative synthesis. I reflected on how this whole experience was incredibly eye-opening and full of surprising discoveries. I kept imagining a picture of myself holding a closed box. Inside this box was all of my allergy-related life experiences. Although I was always aware of the consequences of these allergy-related experiences, I never took the time to explore them or open up the box. I was afraid of confronting them, therefore I avoided thinking that it was necessary to ever explore the feelings those experiences produced. However, this experience has allowed me to finally open up that box and meaningfully explore what was inside. I had this image of a million colorful little butterflies flying out of the box. These butterflies signified all my lived experiences. In the end, these experiences were not as scary as I believe them to be. I wrote the following song "A Million Little Butterflies" to signify how this box that I had carried around with me had finally been opened. This resulted in uncovering so much about myself. Although I will always have this box with me, I no longer feel the need to keep it closed. I can continuously add my lived experiences inside, but I no longer need to be afraid of leaving it opened. The butterflies no longer scare me. I am now aware of them, and I can move on and live my life knowing that they are there.

During my immersion phase, I wrote all of my songs using the piano. However, for my creative synthesis I wanted to challenge myself to write this song using the guitar. This choice truly reflects my growth throughout this whole process, because I embraced a mode of creative expression that felt a little bit outside of my comfort zone. The song was written during one

afternoon, and the process was similar to that of the immersion phase. I began by writing down lyrics, and then recorded myself every time I began playing or singing. Below, are the lyrics to my song, "A Million Little Butterflies". Audio available at the following link:

https://1drv.ms/u/c/a5345e37a91937b4/Ebcy2Hme7_1EhDjBEU98r3YBOFexahj8LmPP
OZFOq-21LQ

A Million Little Butterflies

Feelings held in a box

Carried around for 30 long years

I placed experiences inside

Forgetting they're attached to me at all

I closed the lid and I forgot

I lived my life and just moved on

Never dared to open it up

Afraid of what I may or may not see

Knowing if it stays closed, reality feels less real

There's comfort not to know, and that remained my ideal

But little by little

I lift the lid

To my surprise, a million little butterflies

Show me something new, something about me

To my surprise, a million little butterflies

Things started making sense

I dug deeper, and searched harder

I asked myself the hard questions

Confronted fears, it made me stronger

I started understanding my picture, and the reason for the colors

Like the pieces of a puzzle, each piece meant for the other

But little by little

I start to see me

To my surprise, a million little butterflies

Show me something new, and the me that'll always be

To my surprise, a million little butterflies

I'll always live with a box

And place experiences inside

But now I won't keep it closed

I'm not afraid of butterflies

Limitations

I believe that my main limitation is that I am still a novice researcher, which may limit my insights, my data analysis and my perspective on the use of songwriting in this process. Another limitation for this research was the short time frame, which did not allow for a longer more detailed analysis of the data.

Personal and Professional Implications for the Researcher

After having completed this experience, I have learnt the following; I should not be afraid to explore any of my allergy related experiences or feelings in the future. Should I ever be confronted with anxiety inducing moments in the future, I can take the necessary time to acknowledge my feelings and *then* move on rather than avoid them. Furthermore, this experience has taught me that there is a difference between recognizing your emotions and feeling them. For so long I knew that many of these feelings were present, however I never took the time to acknowledge and allow myself to experience them. It was only when I took the time to feel these emotions that I began learning so much more about myself.

The songwriting component has encouraged me to find different ways to creatively express myself by using analogies to help explain what I want to say. Therefore, it has shown me first hand how songwriting can encourage the flow of expression, and open oneself up to becoming more vulnerable. I believe this experience has made me a stronger songwriter. Songwriting was a particularly beneficial music medium as it allowed me to not only

acknowledge these new insights, but to sit with them and feel them for the first time. Having written five incredibly personal and vulnerable songs throughout this process, I believe this has improved my lyrical writing and it has allowed me to find ways to musically reflect my thoughts and emotions.

In the future, I believe this experience will benefit me professionally, as it has shown me the value that songwriting might have for future clients who experience other forms of health-related anxiety. I have learnt how best to convey my feelings in short, yet impactful sentences. Most importantly, I have come to learn more about myself which hopefully, will decrease the chance of transference or countertransference that may occur when working with clients, as I have taken the time to unpack my own feelings and experiences. Finally, since this process has made me aware of the multi-layered ways in which my food allergy impacts me, I believe it has opened my eyes to understand how one's reality, can impact them in various manners. Therefore, I will take this insight into my music therapy practice, by offering compassion and understanding when working with clients in the future who have various lived experiences.

Themes present within the food allergy related literature showed similarities within my own data findings. Particularly the themes of guilt, hypervigilance, fear, the perceptions of others and the added responsibility. These similarities further validated my own feelings as I discovered the common struggles among the food allergy community. However, the above literature did not seem to highlight the feelings of anger or identity that I have discovered within my own findings.

Recommendations for Future Research

This study has not only allowed me to grow as an individual, but has made me more aware of myself and how I experience, understand, and live with my food allergy. Therefore, the results of this study have highlighted the benefits of reflexive songwriting as a means to further explore internal experiences regarding health related conditions. For this reason, future researchers can explore the effects of music therapy (or group music therapy) with children, adolescents or adults who are experiencing anxiety regarding allergy testing, or the use of songwriting to address anxiety related experiences.

Given the extensive literature regarding the various ways in which food allergies impact individuals, there is a current gap in the music therapy literature related to supporting individuals with life-threatening food allergies. Therefore, there is potential for music therapy to be a powerful and helpful tool. This is why more research on this topic is important. Given that I,

someone with a peanut allergy has learned so much about myself through this process, I believe this could be beneficial for others who have lived similar experiences as me. Therefore, my desire is that new research regarding the use of music therapy with individuals with food allergies becomes a reality.

Closing Thoughts

This journey has allowed me to dive deep into learning more about myself. I have confronted challenging topics regarding my food allergy, however, it has made me stronger. Although this does not change my reality, it has made me aware of my experiences and how I internalize them. In the future, should I ever be confronted with anxiety inducing scenarios, I will be able to understand where certain fears or thoughts are stemming from. I hope this paper is a launching pad for future research on this topic so that individuals with life-threatening food allergies receive the opportunity to experience all that music therapy has to offer.

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